

---

# ARTHRITIS: OUT OF THE MAZE

---



---

## VOLUME IV, PART 3: PUBLIC HEARINGS

---

National Commission on Arthritis and Related Musculoskeletal Diseases

### REPORT TO THE CONGRESS OF THE UNITED STATES

April, 1976

---

U.S. DEPARTMENT OF HEALTH, EDUCATION, AND WELFARE

Public Health Service

National Institutes of Health

**About the Cover Design:**

*According to a legend among the Pima Indians of the Southwest, the great warrior-leader Se-Eh-Ha once constructed a maze with winding, labyrinthine passages, as a refuge from his enemies.*

*That design, shown in the cover of this report, has been used for centuries by the Pima tribe. To them, it also represents a pattern of life, with all its obstacles and frustrations.*

*It may also illustrate the problem of arthritis — with all its obstacles and frustrations.*

Shel, 1/12/78

United States.

**National Commission on Arthritis and Related Musculoskeletal Diseases**

Arthritis out of the maze.

## **Report to the Congress of the United States**

### **Volume IV, Part 3: Public Hearings**

**April, 1976**

**DHEW Publication No. 76-1155**

**U.S. Department of Health, Education, and Welfare  
Public Health Service    National Institutes of Health**

## COMMISSION MEMBERS

Ephraim P. Engleman, M.D., Chairman  
School of Medicine  
University of California  
San Francisco, California

Verna Patton Anthrop, B.S., P.H.N.  
Sacaton, Arizona

K. Frank Austen, M.D.  
Robert B. Brigham Hospital  
Boston, Massachusetts

Rosalind Russell Brisson  
Beverly Hills, California

William F. Donaldson, M.D.  
University of Pittsburgh  
Pittsburgh, Pennsylvania

William R. Felts, M.D.  
George Washington University  
Washington, D.C.

Vivian Floyd Lewis, Ph.D.  
Wilberforce, Ohio

Doris Melich  
Salt Lake City, Utah

Howard F. Polley, M.D.  
Mayo Medical School  
Rochester, Minnesota

Gordon C. Sharp, M.D.  
University of Missouri  
Columbia, Missouri

Marlin N. Shields, R.P.T.  
Latter Day Saints Hospital  
Salt Lake City, Utah

### Ex-Officio:

John D. Chase, M.D.  
Chief Medical Director  
Veterans Administration  
Washington, D.C.

James R. Cowan  
Assistant Secretary of Defense  
Department of Defense  
Washington, D.C.

William Gay, D.V.M.  
Associate Director  
National Institute of Allergy and  
Infectious Diseases  
Bethesda, Maryland

Howard Jenerick, Ph.D.  
Special Assistant to the Director  
National Institute of General  
Medical Sciences  
Bethesda, Maryland

Ronald LaMont-Havers, M.D.  
Deputy Director  
National Institutes of Health  
Bethesda, Maryland

G. Donald Whedon, M.D.  
Director, National Institute of Arthritis,  
Metabolism & Digestive Diseases  
Bethesda, Maryland

### Alternate:

Lt. Col. Oliver J. Lawless, MC, USA  
Chief, Rheumatology Science  
Walter Reed Army Medical Center  
Washington, D.C.

Neil Otchin, M.D.  
Program Chief for Metabolic and  
Renal Diseases  
Veterans Administration  
Washington, D.C.

William H. Batchelor, M.D., Executive Secretary  
Special Assistant to the Director  
National Institute of Arthritis,  
Metabolism & Digestive Diseases  
Bethesda, Maryland





**MARC PLAZA HOTEL  
MILWAUKEE, WISCONSIN  
November 10, 1975**



# TABLE OF CONTENTS

## CHRONOLOGICAL LIST OF WITNESSES MILWAUKEE, WISCONSIN NOVEMBER 10, 1975

	<u>Page</u>
SCHREIBER, Lt. Governor Martin Wisconsin	3-21
BERNHARD, Gerson, M.D. Director, Rheumatic Disease Program, Columbia Hospital	3-23
CARLEY, David, Ph.D. President, Medical College of Wisconsin	3-27
MELVIN, John, M.D. Department of Physical Medicine and Rehabilitation, Medical College of Wisconsin	3-30
RUBIN, Lawrence, D.P.M. Coordinator, Rheumatology Unit, Illinois College of Podiatric Medicine	3-32
SEELHORST, F. Elaine Patient	3-34
MC CARTY, Daniel, M.D. Chairman, Department of Medicine, Medical College of Wisconsin	3-39
ZAHORIK, Janet Patient	3-42
GOLDMAN, Allan, M.D. Chairman, WRMP/WAF Subcommittee; Director, Arthritis Program, Sacred Heart Rehabilitation Hospital	3-44
GORE, Donald, M.D. Orthopedic Surgeon	3-47
PACHMAN, Lauren, M.D. Head of Immunology, Children's Memorial Hospital, Chicago, Illinois	3-48
MC DUFFIE, Frederic, M.D. Rheumatology Research Laboratory, Mayo Clinic	3-50

	<u>Page</u>
HULCE, Ray Vice President, Ford Motor Company; Chairman, Michigan Chapter, Arthritis Foundation	3-56
HUTCHINS, John and LEVIN, Owen Wisconsin Regional Medical Program	3-59
SCHAEFER, Werner President, Milwaukee County Labor Council AFL-CIO	3-61
GELLER, Sam Spouse of Arthritis Patient, North Dakota	3-62
DE ST. AUBIN, Wilfred Pilot Geriatric Arthritis Project, University of Michigan Medical Center, Ann Arbor, Michigan	3-64
JETTE, Alan Pilot Geriatric Arthritis Project, University of Michigan Medical Center, Ann Arbor, Michigan	3-65
LIANG, George, M.D. Rheumatologist, Gunderson Clinic	3-68
EDWARDS, Richard Director of Social Services, Methodist Hospital	3-70
STANDORF, Claudia Milwaukee Dietetic Association	3-72
LORENTZ, Mary Ann Parent of Children with Rheumatic Diseases	3-73
LEMKE, Janet University Student; Patient	3-77
SUNDSTROM, Walter, M.D. Chairman, Medical and Scientific Committee, Wisconsin Arthritis Foundation	3-78
SCHMID, Frank, M.D. Professor of Medicine and Chief of Arthritis and Connective Tissue Diseases Section, Northwestern University	3-81

	<u>Page</u>
GRAZIANO, Victoria Director of Physical Therapy, St. Mary's Hospital	3-83
JACOBSON, Richard President, Wisconsin Arthritis Foundation	3-84
BJARNSON, David, M.D. Rheumatologist, Marshfield Clinic	3-86
GRAHAM, David, M.D. Chairman, Department of Medicine, University of Wisconsin Medical School	3-88
GRUBBE, Arlette Social Worker, Michael Reese Hospital, Chicago, Illinois	3-90
LOVDAHL, John President, Handicabs of Milwaukee, read by John Reddy	3-92
PIGG, Janis Smith, R.N. Nurse Consultant, Rheumatology, Columbia Hospital	3-95
TREACY, William President, Wisconsin Society of Internal Medicine	3-97
HEISS, Marie, R.N. Nursing Specialist, Rheumatology, Columbia Hospital	3-98
HOUSE, Charles Patient	3-100



# SUBMITTED STATEMENTS

	<u>Page</u>
BORG, Ruth Poplar, Wisconsin	3-103
BROTZ, Mrs. Wilbur A. Sheboygan, Wisconsin	3-103
BRODACZYNSKI, Joseph F. Milwaukee, Wisconsin	3-104
COLE, Mrs. James Neenah, Wisconsin	3-105
FASSBENDER, Mrs. W. Sun Prairie, Wisconsin	3-105
FERSTL, Lorraine Madison, Wisconsin	3-105
FLETCHER, Wellington H. Washburn, Wisconsin	3-106
FRYMARK, Patricia J. Milwaukee, Wisconsin	3-106
GARCES, Mrs. P. F. Shorewood, Wisconsin	3-107
GOODRICH, B.	3-108
GRISAR, Carl Milwaukee, Wisconsin	3-109
HAYES, Beatrice A. Wauwatosa, Wisconsin	3-110
JOHNSON, Mrs. L. M. Waupaca, Wisconsin	3-110
JACOB, Leslie Racine, Wisconsin	3-111
KALISH, Bernice Viola, Wisconsin	3-111
KESSLER, Hazel F. Centerville, Ohio	3-112

	<u>Page</u>
KIRCHENBERG, Mrs. Erwin Milwaukee, Wisconsin	3-113
KOWALSKI, Mrs. C. Milwaukee, Wisconsin	3-114
LUECKE, H. E. Appleton, Wisconsin	3-115
MAIER, Karl, Jr. Milwaukee, Wisconsin	3-115
MANNING, Donna J. Wyoming, Michigan	3-116
NAYES, Mrs. Harold Chippewa Falls, Wisconsin	3-117
NELSER, Adrienne Madison, Wisconsin	3-118
POKORNY, Edward J. Milwaukee, Wisconsin	3-118
RAVEN, Mrs. Henry Sheboygan, Wisconsin	3-118
ROCKABRAND, Betty F. Oconto, Wisconsin	3-119
RUEPPEL, Eunice A. Green Bay, Wisconsin	3-120
STAHL, Beatrice M. Milwaukee, Wisconsin	3-120
THORSON, Mrs. Raymond Elroy, Wisconsin	3-121
TRACHLUH, Maria	3-121
BARTELT, Mrs. David West Allis, Wisconsin	3-121
BOWMAN, Gertrude H. Oshkosh, Wisconsin	3-122
BRANDT, Adeline H. Appleton, Wisconsin	3-122

	<u>Page</u>
BROWN, Mrs. Arthur Siren, Wisconsin	3-123
BRUNKE, Adeline N. Madison, Wisconsin	3-124
DEAUCHAMP, Lydia Madison, Wisconsin	3-125
DE YOUNG, John C. Randolph, Wisconsin	3-125
ELLEN, Vera H. Cuday, Wisconsin	3-126
ENNION, Charlotte Berlin, Wisconsin	3-126
FALTER, Ruth O. Janesville, Wisconsin	3-126
FRAZER, Mary Lou Oconomowoc, Wisconsin	3-127
GETTLEMAN, Fred W. Wauwatosa, Wisconsin	3-127
GOLOB, Laverne West Allis, Wisconsin	3-128
HANSEN, Mrs. Arthur H. Green Bay, Wisconsin	3-129
HESS, Evelyn Cincinnati, Ohio	3-129
HOPP, Harley De Pere, Wisconsin	3-130
ISAKSON, Mrs. Kenneth Eau Claire, Wisconsin	3-131
JAGGER, Margaret Milwaukee, Wisconsin	3-131
KEVILL, Hazel Oshkosh, Wisconsin	3-132

	<u>Page</u>
KLAPSTEIN, Mrs. Donald F. Milwaukee, Wisconsin	3-132
LAATSH, Mrs. L. C. Milwaukee, Wisconsin	3-132
LINDER, August J.	3-133
LOHR, Adeline	3-133
MADLAND, L. F., Ph.D. Milwaukee, Wisconsin	3-134
MASHUDA, Marcella Brandon, Wisconsin	3-134
MATTUSHEK, Irma Milwaukee, Wisconsin	3-134
MEIDER, Elsie Sussex, Wisconsin	3-135
MEIER, Walter R. Milwaukee, Wisconsin	3-135
MURPHY, H. Carol	3-136
NECKERMAN, George M. Madison, Wisconsin	3-137
NETZEL, Florence Stevens Point, Wisconsin	3-137
OLTARZEWSKI, Beulah Oak Creek, Wisconsin	3-138
PAAR, Karen Black River Falls, Wisconsin	3-138
PATZER, Esther K. Milwaukee, Wisconsin	3-139
POS, Edward E. Antigo, Wisconsin	3-140
PUZA, Emil A. Milwaukee, Wisconsin	3-140
RADOMSKI, Sylvia Milwaukee, Wisconsin	3-140

	<u>Page</u>
RATHER, Mary Waukesha, Wisconsin	3-141
RAUDWER, John and Edith Milwaukee, Wisconsin	3-141
REITEN, Mrs. Ruber A. Rice Lake, Wisconsin	3-141
ROSENKE, Mrs. Earl Racine, Wisconsin	3-143
RUDKIN, Mrs. Gordon Black River Falls, Wisconsin	3-143
RUFFALO, Mrs. Frank D. Racine, Wisconsin	3-145
SCHMIT, Audrey Port Washington, Wisconsin	3-146
SCHWARTZ, Walter O. Milwaukee, Wisconsin	3-146
SCHOTT, Donna Green Bay, Wisconsin	3-147
SELZER, John W.	3-147
SELL, Mrs. Eugene Elm Grove, Wisconsin	3-147
SMITH, Verle H. Milwaukee, Wisconsin	3-148
SPANGENBERG, Ed Milwaukee, Wisconsin	3-148
STUDE, Norma Milwaukee, Wisconsin	3-148
SWENSON, Gloria Brookfield, Wisconsin	3-148
TRYTHALL, Mrs. D. Elcho, Wisconsin	3-149
VOSICKY, Mrs. C. Geneva, Wisconsin	3-149



	<u>Page</u>
VOY, Ruth V. Horicon, Wisconsin	3-150
WELCH, Kathleen S. West Allis, Wisconsin	3-151
WELCH, K. S. West Allis, Wisconsin	3-152
WICK, Arthur G. Milwaukee, Wisconsin	3-152
ZUEGE, Robert C. Milwaukee, Wisconsin	3-152
ABRAMS, Juanita S. Wausau, Wisconsin	3-153
AUSTAD, William R., M.D. Monroe, Wisconsin	3-153
BAUTCH, Judith L. Madison, Wisconsin	3-154
CAPE, James F. Racine, Wisconsin	3-154
GROSSMAN, Burton J., M.D. Chicago, Illinois	3-154
HARTMAN, Ann Merrill, Wisconsin	3-155
KIERNAT, Jean M., O.T.R. Madison, Wisconsin	3-156
KLEIN, Martha Gray Milwaukee, Wisconsin	3-157
MILLER, Mrs. Clifford	3-158
POTSCHAUER, Lois Omro, Wisconsin	3-158
RUBENSTEIN, Herbert M., M.D. Chicago, Illinois	3-160
RUBENSTEIN, Herbert M., M.D. Maywood, Illinois	3-161

	<u>Page</u>
RUNHOLM, Eugene A. Waupun, Wisconsin	3-162
RYALL, Mrs. E. V. Kenosha, Wisconsin	3-162
STARK, Mary Rita	3-162
STEVERWALD, Viola, R.N. Adell, Wisconsin	3-163
TORINUS, Jack B. Appleton, Wisconsin	3-163
YOST, William A., Jr. Wauwatosa, Wisconsin	3-164
BARTLEIN, Beverly Muskego, Wisconsin	3-165
DUXBURY, Henry W. and Rosa L. Tomahawk, Wisconsin	3-166
GINTHER, James E. Akron, Ohio	3-167
KRYZENSKE, Frank Sheboygan, Wisconsin	3-168
LOPEZ, Basillio Milwaukee, Wisconsin	3-168
BREITZMAN, Janet A. Milwaukee, Wisconsin	3-169
BURKE, Mrs. R. G. Milwaukee, Wisconsin	3-170
CZECH, Paul C. Wauuatosa, Wisconsin	3-170
DE BENEDICTIS, Marcia Cedarburg, Wisconsin	3-171
FRIEND, Henry C. Milwaukee, Wisconsin	3-171
HAYDEN, Paul W. Slinger, Wisconsin	3-171

	<u>Page</u>
HEMMENT, Marguerite, R.N. Lake Geneva, Wisconsin	3-172
KLOPPMANN, Vera A. Milwaukee, Wisconsin	3-173
KRUSE, Audrey J. Milwaukee, Wisconsin	3-173
LINK, John H. Evanston, Illinois	3-173
MATTIOLE, Mrs. Angelo Kenoshi, Wisconsin	3-174
MENGEL, Mary Fond du Lac, Wisconsin	3-174
NELSON, Mrs. Wendel Green Bay, Wisconsin	3-175
NERO, Doris Brookfield, Wisconsin	3-176
PANKRATZ, Margaret Sturgen Bay, Wisconsin	3-176
SUMMER, Mrs. Howard L. Racine, Wisconsin	3-178
THIELMANN, Dorothy Chilton, Wisconsin	3-179
VIG, Rosalyn J., R.N. Viroqua, Wisconsin	3-179
VOIGHT, Christine Kenoshay, Wisconsin	3-180
WILSON, Robert J. Madison, Wisconsin	3-181
WRUCK, Chris Milwaukee, Wisconsin	3-181
ZOLORSKI, Eleanor St. Francis, Wisconsin	3-182

	<u>Page</u>
RITTER, Mrs. Kenneth Cedarburg, Wisconsin	3-182
SCHLEVENSK, James	3-183
STARK, Lewis Madison, Wisconsin	3-184
BERG, Myrtle M., R.P.T. Beaver Dam, Wisconsin	3-185
BLANK, Lois La Crosse, Wisconsin	3-186
BOSSHARD, Mina I. Janesville, Wisconsin	3-186
BULIN, Ann Milwaukee, Wisconsin	3-187
CHERNOV, Mimi Milwaukee, Wisconsin	3-187
COLLINS, Lorraine	3-193
FORBES, Cynde Milwaukee, Wisconsin	3-194
FRANK, Lydia F. West Allis, Wisconsin	3-194
GIBBON, Irene Cedarburg, Wisconsin	3-195
HAMACHEK, Mrs. Frank Keweenaw, Wisconsin	3-196
DAVIES, Loree and HANSON, Erica Madison, Wisconsin	3-196
HARLOFF, Helen L. Madison, Wisconsin	3-197
HAUGEN, Marilyn Edwina, Minnesota	3-198

	<u>Page</u>
HOARD, Mary Grace Fond du Lac, Wisconsin	3-198
HOUGH, Robert E. Greendale, Wisconsin	3-199
JAKUBOWSKI, Althea Oshkosh, Wisconsin	3-199
JORGENSEN, Eleanor C., R.P.T. West Allis, Wisconsin	3-200
KANAROWSKI, John Germantown, Wisconsin	3-201
KAPPELMAN, Mae Milwaukee, Wisconsin	3-201
KLAMER, Lorraine Racine, Wisconsin	3-202
KRING, Carol Sturgeon Bay, Wisconsin	3-204
MEIKLE, Irene Dodgeville, Wisconsin	3-206
MINOR, Mrs. W. P. Mequon, Wisconsin	3-206
MORITZ, Mary Milwaukee, Wisconsin	3-206
MOZE, Frank James Milwaukee, Wisconsin	3-207
MULLARKY, Mrs. H. Milwaukee, Wisconsin	3-207
NELSON, Lorraine Milwaukee, Wisconsin	3-207
OHLSEN, Minna Milwaukee, Wisconsin	3-208
PETERSON, Douglas Waukesha, Wisconsin	3-208
POHL, Evelyn Greendale, Wisconsin	3-208



	<u>Page</u>
SCHMIDT, Sylvia E. Campbellsport, Wisconsin	3-209
SEAMANS, Carol Reedsburg, Wisconsin	3-210
SPIRO, Joanna H. and HAYDEN, Mary Claire Milwaukee, Wisconsin	3-210
STENGER, John G. Milwaukee, Wisconsin	3-211
TIVANOVAK, John J. West Allis, Wisconsin	3-212
WEISS, Mrs. Sandy East Troy, Wisconsin	3-212
WIEGAND, Annette J. Sheboygan, Wisconsin	3-213
WIEGARD, Annette J. Sheboygan, Wisconsin	3-214
FULLER, Jean F. Oshkosh, Wisconsin	3-214
KUNZE, Winifred Elm Grove, Wisconsin	3-214
KUNZE, Winifred Elm Grove, Wisconsin	3-216
KUOLT, Lorraine H. West Allis, Wisconsin	3-216
SOLBERG, Dorothy F. Wauwatosa, Wisconsin	3-217
SUNDE, Mrs. Jack River Falls, Wisconsin	3-218
WICKERT, Mrs. W.	3-218
CORNWELL, Susan J. Hales Corner, Wisconsin	3-218

	<u>Page</u>
DYKEY, Charles E. Chicago, Illinois	3-219
GRISAR, Mary Milwaukee, Wisconsin	3-219
VAN ROSSUM, Marie Milwaukee, Wisconsin	3-221
SAUER, Reverend W. P. West Bend, Wisconsin	3-221
ARMSTRONG, Elizabeth	3-222
BATES, Carol Ladysmith, Wisconsin	3-222
BERG, Mrs. Eugene Ripon, Wisconsin	3-223
BETHEL, Rose Oregon, Wisconsin	3-223
BOYNTON, Mrs. Ardis Beloit, Wisconsin	3-223
BROOKINS, Bessie Sheboygan, Wisconsin	3-224
BUSH, Lucille E. Robinson Milwaukee, Wisconsin	3-224
CALLAN, Phylis Milwaukee, Wisconsin	3-228
CLARK, Vivian Milwaukee, Wisconsin	3-228
CLOCHESY, John M. Fond du Lac, Wisconsin	3-229
ENNIS, Ruby Nelson Sturgeon Bay, Wisconsin	3-229
EURICH, Mrs. Sheboygan, Wisconsin	3-232
FOLEY, Eloise G. Sun Prairie, Wisconsin	3-233

	<u>Page</u>
FORSYTH, Ethel Waukesha, Wisconsin	3-234
GAROT, Lil Green Bay, Wisconsin	3-234
HANNI, Arlene Cuba City, Wisconsin	3-235
HAUGEN, Clarion W. Beloit, Wisconsin	3-235
HAUGEN, Mabel	3-236
HELM, Don Oshkosh, Wisconsin	3-236
HOUSE, Mrs. Frank	3-237
HUETEL, Mrs. E. A. Wabeno, Wisconsin	3-237
KOTHBAUER, Joan Eau Claire, Wisconsin	3-238
MARCKS, Fern Pepin, Wisconsin	3-239
MATTHIAS, Mrs. Donald Berlin, Wisconsin	3-239
MILLER, Alma Rose Reedsburg, Wisconsin	3-239
MORRELL, Iva West Allis, Wisconsin	3-240
NEUMAN, C. E. Milwaukee, Wisconsin	3-240
NIEMANN, Carol Winneconne, Wisconsin	3-241
NILES, Mrs. Richard D. Madison, Wisconsin	3-241
NUHN, Shirley N. Milwaukee, Wisconsin	3-242
PELT, Cora V. Wauwatosa, Wisconsin	3-243

	<u>Page</u>
PIOTROWSKI, Mrs. Edward Greenfield, Wisconsin	3-243
RAYMER, Clare Rice Lake, Wisconsin	3-244
ROGAHN, Florence	3-244
SAGE, Mrs. John F. Janesville, Wisconsin	3-245
SAUER, W. P. West Bend, Wisconsin	3-246
SHADE, Evelyn Lyndon Station, Wisconsin	3-248
SPINNEY, Viola Hypertus, Wisconsin	3-248
STECHMESSER, H.	3-249
STRANDE, Robert Trevor, Wisconsin	3-249
SUDBRINK, Arlinda Sheboygan, Wisconsin	3-250
SWEENEY, Mrs. Lester West Allis, Wisconsin	3-250
UNDERWOOD, Carl P. Whitewater, Wisconsin	3-251
WORBY, Evelyn S. Hayward, Wisconsin	3-251
ROBERGE, Mrs. Donald Rice Lake, Wisconsin	3-251
ZIOLKOWSKI, Pearl South Milwaukee, Wisconsin	3-252
MEMBERS OF AN ARTHRITIS CLASS Milwaukee, Wisconsin	3-253





## P R O C E E D I N G S

DONALDSON: I would like to call this session of the public hearings of the National Commission on Arthritis and Related Musculoskeletal Diseases to order. There are a few basic ground rules that we have to exist by in order to have the information appropriately recorded so that later on it can be included in the testimony that we will present to Congress in our final report. Therefore, I would ask that all persons appearing before the Commission clearly state their full name, their title, their organizational affiliation, and their address. We also would ask that you submit a written statement so that your comments may appear in the official record of the hearings. Unfortunately, we must also ask that you limit the amount of time of your presentation to about four minutes, so that the Commissioners may have a chance to ask questions and in order that we may be able to give everybody their time. We are most appreciative that so many people have asked for the opportunity to appear before the Commission, and we are anxious to hear from all of you. It is a real pleasure to introduce the lead-off witness, who is the Lieutenant Governor of the State of Wisconsin, Mr. Martin Schreiber.

### TESTIMONY OF LIEUTENANT GOVERNOR MARTIN J. SCHREIBER WISCONSIN

SCHREIBER: Dr. Engleman and members of the National Arthritis Commission: Welcome to Wisconsin. I am Martin J. Schreiber, Lieutenant Governor of Wisconsin. I trust that your visit here today will be both fruitful and enlightening.

I am neither an expert in rheumatology nor in the delivery system for treatment of rheumatic diseases. My appreciation for the ravages of arthritis and problems faced every day by arthritic persons is only developing. I feel, however, that I can speak to certain problems which are so basic that they may be somewhat overlooked in the preparation of the National Arthritis Plan. My purpose this morning, then, is to welcome the Commission and touch upon one aspect of rheumatic disease care which must not be neglected.

Wisconsin is similar to many other states in that its health care resources are stretched far too thinly. This is especially true in the more specialized and sophisticated health care disciplines. But others here today will speak to this problem far better than I can. But beyond medical resources lies the equally important area of delivery of the many public and private services which affect the treatment and rehabilitation of patients. In the area of service delivery, one of the largest components is state government.

In developing a National Arthritis Plan, the Commission must also consider the problem of how best to organize, coordinate, and deliver services to have maximum beneficial impact on patients.

For example, State government in Wisconsin has a variety of agencies and services which assist a great many different people. In the area of health and human services particularly, there is a tendency toward

fragmentation of these efforts as they deal with people. The result is too often that separate agencies work on the similar problems, without coordinating their efforts. We are constantly striving to reduce this fragmentation, but it remains with us nonetheless.

The care, treatment, and rehabilitation of arthritic patients is a prime example of this problem. Rheumatology remains an emerging field. The existing structures and programs were developed without benefit of the lessons it now can provide.

The person afflicted with arthritis may encounter public health and education programs, medical assistance programs, various acute and chronic institutional programs, vocational rehabilitation, and more. Further, people who counsel arthritics or who actually participate in therapy may represent a variety of public and private entities, often with no sense of continuity between them.

Unfortunately, too rarely is the whole person treated, addressed, and informed in an appropriate manner. Nowhere does there exist today the capacity for such large scale coordination focused on all the resources within any state or region.

The Commission would be advised to consider the necessity for funding consortia of agencies and services which would not only represent the vast needs for research and education in rheumatic diseases, but would also pull together the myriad of public and private programmatic resources in the area of rheumatic diseases.

State government in Wisconsin has learned this lesson and has attempted to deal with the need for coordination in other long neglected areas of social concern. The best example was the Governor's Task Force on problems of people with physical handicaps. This outstanding Task Force tackled the problem of civil rights of the handicapped and produced a document which cut across all disciplines and subject areas to identify the specific areas where remedial action by Government must be taken. The results of this task force will help those people afflicted with arthritis to exercise their full rights of access, participation, and growth as citizens.

As this coordinated effort has helped raise the sensitivity of State government to new kinds of problems, so should the Commission follow a broad approach in cutting across present categories to confront the entire needs of arthritic citizens.

Whether symposia are organized or more structured experiences are offered, a consortium made up of providers, consumers and planners could work to better tie together what currently exists and to plan for using future resources.

If there is one message that I wish to present to the Commission, it is that limited resources must be spent where most effective. Attention to the development of coordinated networks of services and programs would be a wise investment for the entire nation.

I thank you for the opportunity of appearing before you today.

DONALDSON: Thank you again. We certainly will take your message to heart, and it is certainly a great way for us to start our hearings here. Are there any questions from the Commissioners? Yes.

SCHREIBER: I might add that we have one other additional experience; that is primarily with the elderly, where we are attempting to provide services for them in their own homes. We find out that there really is a great lack of understanding of what current services exist; there is lack of coordination of these services and there is, on many occasions, a lack of awareness that these actual services do indeed and in fact exist. With that, then, not only are they available, but a great amount of human suffering and misery follows because of the fact that people are not aware or that they are not coordinated.

DONALDSON: Again thank you very much for taking time out of your busy schedule to come. Now I would like to ask the following witnesses to come down and occupy the chairs at the table; and while you are coming down I will also ask the Commissioners to introduce themselves to you. If Dr. Gerson Bernhard, David Carley, and Dr. John Melvin -- we will take a moment now so that you may be aware of who the individual Commissioners are.

I am Dr. William Donaldson. I am an orthopedic surgeon from Pittsburgh, Pennsylvania.

MELICH: I am Doris Melich from Utah. I am the president of the Utah Arthritis chapter out there.

SHIELDS: I am Marlin Shields. I am a physical therapist and I am representing the allied health professions on the Commission.

JENERICK: I am Dr. Howard Jenerick, a staff member of the National Institutes of Health.

LEWIS: I am Dr. Vivian Lewis, retired university professor of kinesiology, physiology of exercise.

SHARP: Dr. Gordon Sharp. I am a rheumatologist at the University of Missouri, in Columbia, Missouri.

DONALDSON: And now Dr. Bernhard, if we may hear from you please.

TESTIMONY OF  
GERSON C. BERNHARD, M.D.  
DIRECTOR, RHEUMATIC DISEASE PROGRAM  
COLUMBIA HOSPITAL

BERNHARD: The primary concern of medicine is the provision of comprehensive health care. In the face of extreme specializations, physicians continue to look for means to meet the total needs of patients and to bring scientific advances of multiple specialities to bear on a



single medical problem. The magnitude of the health care problem in rheumatic diseases is such that approximately 10 percent of the population of the United States is afflicted with this group of 87 disorders, covering all types of arthritis, muscle and connective tissue diseases, and in all age groups.

While there are about 2300 physician members of the American Rheumatism Association, the number of practicing physicians devoting the majority of their time to the care of rheumatic disease patients is much less -- perhaps not more than 800. Only a small number (a little over 3 percent) of rheumatic disease patients are seen by these specialists. The majority are cared for by physicians not specifically trained in rheumatology. The problem is to find a means of utilizing the small number of specialized physicians in a manner which will bring to the greatest number of patients not only the best rheumatologic experience, but also the best of other disciplines affecting the course of treatment and rehabilitation in its broadest sense.

The challenge is to implement a program for the total treatment of patients, and provide professional education and advance knowledge about these diseases and their management.

One of the goals of the National Arthritis Act must be the education of all health professionals about the care of rheumatic disease patients. In particular, speciality training of physicians, nurses and therapists must be emphasized to expand our knowledge of these diseases, to teach subsequent professionals, and to provide care directly.

It is equally important to transfer the most current scientific information to the care of patients with these diseases. We are challenged to provide comprehensive care with the most efficient utilization of our professional resources. Therefore, another major goal of the National Arthritis Act must be the support of programs that will accomplish this end.

The care of rheumatic disease patients requires the services of several specialists, including physicians, surgeons, and allied health professionals who may work in different groupings depending upon the medical or surgical problem at hand. This group of specialists cannot replace the primary physician, but must function as consultants even though the chronic nature of the majority of rheumatic disorders necessitates ongoing treatment. Well trained physicians and surgeons can diagnose, treat, and refer to other specialists from their own offices. The medical care delivered may be of good quality, but when separated from other members of the team, the care is fragmented and often inefficient for both patient and physician. Furthermore, the care is not comprehensive because total care depends upon a multi-discipline approach. Each specialist must contribute the most advanced prospectus of his discipline.

The frequent and easy interchange between specialists working as a team broadens their purview, improving their capability to meet the patient needs and prevent their own obsolescence.

The majority of rheumatic diseases are cared for on an ambulatory basis. Outpatients as well as hospitalized patients require the sophisticated and costly diagnostic and treatment capability of a well equipped general hospital. It is in such hospitals that training opportunities may be possible for both general and specialized physicians, general and specialized nurses, as well as physical and occupational therapists. Since physicians and allied health professionals in a rheumatic disease program provide consultative care and a professional teaching service, they must serve in a regional context. Therefore, the hospital in which such a comprehensive program is to be located should be an institution serving a fairly large population. It is a more efficient use of scarce resources to concentrate specialists in a few hospitals of a region rather than attempting to staff programs in all institutions. Collecting specialists in one place provides an atmosphere for professional critique which stimulates excellence.

It has been suggested that the care of rheumatic disease patients in the United States has been compromised because it has been predominately outpatient in nature. Yet, for economic and social reasons there has been a progressive trend to provide as much medical care on an ambulatory basis as possible. One of the major challenges of inter-disciplinary rheumatic disease programs, such as I have outlined, is to provide just as complete investigation and intensive applications of treatment for both hospitalized and non-hospitalized patients. This requires careful coordination with home care agencies, the community, and other institutions. Inpatient rheumatic disease units in which exemplary care is provided and taught to both patients and families should be developed as the initial step in implementing the regional rheumatic disease programs. A liaison must then be established with community health services such as Visiting Nurses' Associations, public health nurses, public schools, and outpatient rehabilitation facilities. In this way there can be continuity of care and extension of professional education beyond the confines of the hospital.

Funding through the National Arthritis Act can be critical to the growth of this type of health care system. Financial support is required for the inaugural administrative costs. Most of the ongoing costs for services can be recovered from patient care revenues. Therefore, this portion of the program can become self sustaining. Support for education, both professional and of patients, will be required on a continuing basis. Finally, any experiments in care delivery, especially in relation to home care agencies, need funding on an individual basis. A master formula for these regional programs cannot be applied uniformly throughout the United States. Needs and local situations will vary. Guidelines must therefore remain flexible and responsive to local and regional peculiarities.

The primary challenge to implement a program providing comprehensive rheumatic disease care for patients of a region can be met by utilizing the existing resources, by collecting in one location the necessary specialists, and by helping them develop the administrative and physical structure. This program may not provide total care less expensively than the current fragmented medical care system. However, this program does provide more efficient and effective use of highly skilled, specialized personnel. Hence, a greater number of patients may benefit from their



skills. Furthermore, the association of teaching and research in a health care delivery setting will insure rapid translation of new information into effective disease management.

DONALDSON: Thank you very much. One of the questions that occurs to me as I listen to your presentation -- which certainly is a strong one in support of centers that are located within health care units rather than a separate unit -- can you give us some idea as to how large a geographic population you would conceive such a center might serve?

BERNHARD: Depending upon the size of the center in terms of inpatient beds, I would assume that one would need such a collection of perhaps 20 inpatient beds, 2 or 3 rheumatologists to cover an area of 250 to 300--or 400--perhaps 500 thousand population. Therefore, in a metropolitan area such as this, we would probably need, I would say, at least three such centers, perhaps four.

BATCHELOR: I would like to ask Dr. Bernhard -- in your presentation you spoke about the need for some central action to the arthritis plan, but the need to keep this properly dealt with to local parenthesis concerned--that you may know, that the same day the Arthritis Act was signed into law that you had another law passed that had to do with the on a regional basis develop and help fill the vacancies, and so on. So that, in fact, Federal support or efforts of this kind, where the impact on patient care will indeed, according to this law, be subjected to local planning. I would like to ask you whether there has been any progress in this region for the development of health care agencies on the rheumatic act?

BERNHARD: It is my understanding, and as corporate member of the Comprehensive Health Planning Agency of Southeastern Wisconsin, this will apparently be the agency that will assume and accept that responsibility under the new legislation. This is an organization which is voluntary and has been functioning for the last several years; and it will now gain additional importance.

SHIELDS: I would like to ask Dr. Bernhard -- what do you see as the current major problems that interfere with your extending your expertise and influence into a larger region around you?

BERNHARD: I think it really comes down to not having enough people in an organized situation to do this. We need a few more rheumatologists, we need more expertise in nursing and physical medicine, and we need the administrative structures to permit us to utilize our physician time more completely.

SHIELDS: Early on you would see some type of training program that would generate more of the professionals as a major need?

BERNHARD: I think this is a part of the function of such an -- of such a program, too; not just as trained specialized physicians, but to also train specialized people in the allied health professions in this kind of a health care delivery setting.



DONALDSON: Well, thank you very much. Now we have the pleasure of hearing from David Carley, who is the president of the Medical College of Wisconsin.

TESTIMONY OF  
DAVID CARLEY, Ph.D.  
PRESIDENT, MEDICAL COLLEGE OF WISCONSIN

CARLEY: My own interest in medical affairs really began when Governor Lucey, of this state, appointed me chairman of the Task Force on Health Policy and Planning in 1971. I appear before you today not only as President of The Medical College of Wisconsin, but also as an arthritic, since I myself suffer from gout.

As you know, research in recent years has resulted in the ability to diagnose my disease, gout, with exquisite precision. Not only are there drugs available to completely control the symptoms and rid the body of excess uric acid, but the mechanism of action of most of these drugs is known with pinpoint certainty. Thus I am fortunate in that gout is one of the most treatable diseases in all of medicine. Unfortunately, there are many other types of arthritis which lead to crippling, loss of work, and personal suffering, for which treatment is not so far advanced. Research support for arthritis has been dwindling relative to what it was only a few years ago. It is imperative that research in arthritis and arthritis-related areas be intensified in order to improve the less than satisfactory treatment for many types of arthritis which exist in such enormous numbers in the population.

An even more important priority is the education of more physicians who are skilled in the delivery of arthritis care. It is well and good to speak of a multidisciplinary approach to arthritis care, but any multidisciplinary team requires a leader. The leader unquestionably should be a skilled rheumatologist who has had adequate training and background in general internal medicine followed by two years of intensive work in the arthritis field. In the case of children, expert care could be rendered by a team captained by an internist-rheumatologist or by an even scarcer individual, the pediatrician-rheumatologist. There is no way at the present time to deliver in the State of Wisconsin the knowledge that now exists, let alone rapidly apply future advances in knowledge of prevention, diagnosis, and treatment. We are fortunate, here in Milwaukee, and at our Medical School, to have one of the nation's premier scientists in rheumatology, Dr. Danial McCarty, the chairman of our Department of Medicine.

There is a comprehensive rheumatology program developing at the Medical College of Wisconsin. The first fellow in the field of arthritis and rheumatism ever trained in the State of Wisconsin began training in July 1975, and will see patients as a fully qualified consultant in July 1977. The University of Wisconsin, at the present time, has only one rheumatologist who is vastly overworked, and by himself cannot mount an effective training program. Thus, for a State of 4.6 million people, we have exactly one physician in training at the present time. There are fewer than 10 qualified rheumatologists practicing in the State, including

those full time in the two medical schools whose patient service commitment is reduced by virtue of their teaching and research responsibilities. I suggest that we need 50 -60 additional rheumatologists in this State.

The training mission in Wisconsin appears enormous. I would like to see sufficient resources generated by virtue of the National Arthritis Act to assure a sound academic unit in each of the two medical schools in the State with sufficient training, so that this enormous deficiency in the ability required to deliver even what is known at the present time to the population can be eliminated in our lifetime.

Thank you very much.

DONALDSON: Thank you. Do any of the Commissioners have any questions?

MELICH: Yes, Dr. Carley -- you mentioned the training of the rheumatologists with the emphasis on internal medicine -- you used the term internal physician. To what extent should the rheumatologist be involved with external or physical medicine?

CARLEY: Well, I mentioned, Dr. -- I mentioned both internal medicine, I also mentioned pediatric medicine. I certainly would not limit the application or the education of rheumatology to internal or pediatric medicine.

DONALDSON: Bill

BATCHELOR: In your introduction, you mentioned that you had a role in 1971 in health policy and planning for the State, Federal -- did that role continue?

CARLEY: Well, that particular role didn't, Dr. That Health Policy Task Force started in 1971 and came up with some hundred and seventy-five recommendations to the State legislature, about half of which -- then the subsequent two sessions have been acted. Since then I have been chairman of the Medical Education Review Commission of the State, and from one thing led to another; and I became president of the Medical School. But there are a number of research reports hearings we held all over the State. If your are interested in the publications of those, we would be happy to deliver them.

BATCHELOR: This is part of our continuing education, as well as saving our time, too; and we would appreciate very much having from you the publication that came from that.

CARLEY: Be happy to do that. I would be glad to give them to you.

DONALDSON: Gordon.

SHARP: Dr. Carley, assuming that resources, at least initially, may not be too plentiful, what would you consider the top priority in the early phasing in of the programs of the National Arthritis Act?

CARLEY: Excuse me Dr., you say, what would I consider or what did I consider.

SHARP: What would you consider the highest initial priority for funding under the Arthritis Act?

CARLEY: Let me say that I probably am not competent to be commenting on the allocation of resources and scarce funds. I have a strong bias and I think I alluded to that with regard to education. I would not be prepared to say that I think education is the first among so many things that need equal treatment, and want to be honest and candid with you on that score. We feel, and as I said, that education is a tremendous and important beginning. Whether or not certain aspects and service delivery systems are more important at this point, I frankly would not be competent enough to say; but I would like to leave a strong implication of necessity in the educational field.

SHARP: Well surely you have indicated a great lack of sufficient education manpower to do the job at this point.

CARLEY: With only -- right -- with only one physician in training, precisely, that statistic is so alarming.

MELICH: I have one other question: Are the medical -- does the Medical College have such a rapport that they are beginning to create more interest among other physicians to go into rheumatology as a practicing field?

CARLEY: I would like to be able to say the answer to that is yes. Dr. McCarty and my associates here at the table, both members of our faculty, are probably better able to answer that. I think the answer is yes, doctor. To what extent we can induce other physicians in other fields to become interested, I myself am not all that aware. But I think that with those who are appearing on the program together with me and others -- I think they will be able to give you a very qualified answer to that.

DONALDSON: We have time only for one more question.

MELICH: This is just a brief one. I would like to know, is it because of manpower that you only have one person training right now, or is it because they lack the motivation or the need for financial assistance?

CARLEY: Well, I think our financial assistance program is the one that is critical. I don't think that there is lack of motivation. I see in the two gentlemen at the table with me, both esteemed members of our faculty in various fields, and Dr. McCarty, who will follow me as chairman -- I am impressed. I have only been at the medical school for eight months, and I am impressed with the motivation not only by our faculty, but the encouragement in this community toward areas of arthritis. But I think the message and the burden of the problem is the great cost -- comparative cost -- in terms of training physicians of the particular area; and also the lack of funds. Fifty to sixty that I mentioned in my



comments is a large number, but not anywhere near too large to serve this State. And it is a matter principally financed, not of motivation, or manpower -- I think is what I think you meant or said in fact when you met (inaudible).

DONALDSON: Well thank you very much. Now we will hear from Dr. John Melvin.

TESTIMONY OF  
JOHN L. MELVIN, M.D.  
DEPARTMENT OF PHYSICAL MEDICINE AND REHABILITATION  
MEDICAL COLLEGE OF WISCONSIN

MELVIN: Mr. Chairman, Ladies and Gentlemen: Arthritis to a large extent represents a chronic disease with which an individual must deal for the rest of his or her life. As such, episodic health or rehabilitation care of the type traditionally used in medicine does not serve the needs of this group satisfactorily. What is needed, in my view, is a system of support, medical and rehabilitative, which is continuous and aimed at maximizing the individual's function throughout the course of the disorder.

One of the key elements to such continuity is education of the patient regarding his illness and its care. Primary responsibility for learning how to utilize medications and how to function in a manner minimizing stress on involved joints must be transferred to the patient. This involves not only initial education early in the disease, but also regular periodic reviews: patient continuing education if you like. To accomplish this, health professionals must be trained in educational procedures which induce the recipients to significantly alter behavior, systems for monitoring success and validity of procedures must be developed, and funding resources must be available to support such activities through usual insurance mechanisms.

The chronic nature of arthritis leads to the need for a wide range of maintenance programs to provide a satisfactory quality of life and to reduce the likelihood of institutionalization. An example includes review of and perhaps administration of physical therapy procedures to maintain strength and joint motion. Another would be the availability of prepared meals and assistance in maintenance of one's living quarters. Another would be the availability of meaningful day activity programs. Such programs can include socialization, recreational, avocational, and even limited vocational elements. At the present time, the allocation of resources to maintenance programs for physically impaired individuals is quite limited.

The physical changes included by arthritis frequently cannot be totally eliminated, leading to the need for adaptive equipment and environmental modifications. This may mean such things as casted shoes, altered eating utensils, special kitchen modifications, or general relief from architectural barriers. To accomplish the needs in this area, similar strategies as outlined above are needed; patient education, professional education and involvement; societal understanding and

interest, systems development, and availability of financial support for such activities.

The points I have mentioned relate to the ongoing care of one with chronic illness. They are designed to prevent and minimize disability. I feel at present our focus has been episodic and disease oriented without sufficient attention to continuous concern for the problems of the involved individuals.

DONALDSON: Thank you very much. Are there questions? Yes.

MELICH: I am particularly interested in what you are discussing. I would like to ask you -- what approach do you have to the emotional and psychological problems of the patients that come with definite upsetting kinds of things? What do you do? Do you have a definite program for this sort of thing?

MELVIN: Well we have what we hope is a team approach which includes people from psychology, social work, in addition to all the other medically oriented professionals. The role of the psychology and social work people is not only to work with the patients as needed, but to work with the professionals in terms of helping them learn how to deal with the emotional and psychological problems of these patients; so that we attempt to get a certain empathy and involvement of the entire group of people, each trying to reinforce the other. So, I think that our system is basically encompassing a broad range of professionals with a broad range of objectives. Our objectives are not limited to, for instance, keeping information minimal -- to a minimal level, but rather to deal with broader role definitions of the individual. Are they working or do they want to work; how are they relating to their family; are they assuming their roles as parents; as mother; things of this nature.

MELICH: Thank you.

DONALDSON: Yes.

SHIELDS: You talked about patient education and of course the value of it. One of the problems that I can see is that in the majority of cases it is not paid for, and therefore, it becomes a very difficult problem. Do you have any help -- I am sure that we are going to have to convince insurance companies that this will cut costs; rather than just add costs and do you have any feelings in this regard or any help that you would like to talk about?

MELVIN: Well, yes, the problem basically, as I view it, is that in chronic illness in general and arthritis in specific case, there is too much of a carry over of the tradition of what medicine does to the patient rather than the patient assuming responsibilities for what happens. Now the reason that I put right after that we have to train professionals in things that actually change behavior of people -- I am not sure we even know what are the best educational procedures for this now -- was that we have to have an evaluation component to start to monitor whether we are doing well or not. This goes back into the total need for a system that not only sets up its objectives, but then monitors how it meets those

objectives; and so I don't have the perfect answer to it. We are trying all sorts of things, like problem oriented records, monitoring, program evaluation of the type that CARF and some of the other organizations are working with; but we have not answered the problem.

DONALDSON: Well thank you very much. I am afraid we must move on. We certainly appreciate all three of your being here and giving us this information.

Now if I could ask Elaine Seelhorst and Dr. Daniel McCarty to join Dr. Rubin at the table. Dr. Rubin if you will, please.

TESTIMONY OF  
LAWRENCE M. RUBIN, D.P.M.  
COORDINATOR, RHEUMATOLOGY UNIT  
ILLINOIS COLLEGE OF PODIATRIC MEDICINE

RUBIN: I am pleased to have this opportunity to inform the Commission of podiatry's involvement with the problem of rheumatic disease. I would also like to convey to the Commission the profession's desire to cooperate with it and to contribute to those future programs directed against arthritis and related diseases that the Commission will initiate.

The podiatrist is an independent provider of health services whose practice consists of the diagnosis and management of diseases and disorders of the feet. He is educated to render these services through pre-professional and professional academic curricula, and through clinical training which parallel that of medicine and dentistry. There are approximately 8,000 podiatrists in the U.S.A., most of whom are engaged in private practice, and who provide upwards of 24,000,000 patient visits annually. The majority of patients treated by podiatrists are between the ages of 17 and 64 years (57.5%), with a significant percentage being over 65 years (30.75%).

In the course of the practice of podiatric medicine, the podiatrist generally sees more foot abnormalities than any other member of the medical team. An especially high percentage of the conditions he sees are either arthritic in nature or related to arthritis. This is understandable when one considers that the feet house approximately 66 of the body's joints, and the major arthropathies of degenerative joint disease, rheumatoid arthritis and gouty arthritis all have a particular predilection for the feet.

Persons suffering arthritic foot pain or disability, whether aware of its arthritic causation or not, frequently seek relief from the podiatrist, and therefore a significant proportion of the clinical practice of podiatric medicine is rheumatologic in nature.

While arthritic involvement of the feet causes considerable suffering, disability, and economic impact, the prevailing opinion in both podiatry and medicine is that it has received proportionally little attention from the general medical community when compared to arthritic manifestations of other regions of the body. Until virtual crippling exists, it is not



unusual for arthritic foot complaints to be perfunctorily attributed to other causes such as "flat feet" or "dropped metatarsal arches." Equally prevalent is the situation in which these complaints are handled with little more than the recommendation for a sturdier or better fit shoe. Because there is an extensive armamentarium of effective therapeutic and deformity-preventing measures which could be utilized, this tendency to devote minimal concern and attention to the feet is regrettable.

The situation is further complicated by a tendency for the public in general to attempt self-treatment of their foot ailments with medications and remedies bought on the basis of advertising claims, or to follow non-professional advice from shoe clerks and commercial appliance technicians. These factors all too often account for an unfortunate delay in the diagnosis of foot-manifest arthritis and a failure to institute those therapeutic and preventive measures which are available and capable of alleviating unnecessary pain and deformity.

The podiatrist, however, can and does render a comprehensive and integrated approach to the foot problems of the arthritic patient and can often obviate the unfortunate sequelae of delayed diagnosis and inadequate therapy.

A representative example of the podiatrist's role as a member of the arthritis medical team can be seen in the care of the patient with foot manifestations of rheumatoid arthritis. Because the clinical symptoms of this disease often first appear in the feet, the podiatrist's high index of suspicion in the common complaints of arch and heel pain, "metatarsalgia", bunions, and other seemingly minor foot problems often leads to its early detection. Prompt referral to the medical members of the arthritis team can now result in immediate attention to the constitutional elements of the disease and involvements of areas other than the feet. Meanwhile, using those therapeutic measures which are universal in arthritis management, and those special medical, biomechanical, surgical and palliative means the profession of podiatry has developed through its singular concentration upon the feet, the podiatrist is in a unique position to initiate therapy and measures aimed at preventing future deformity and disability.

In conclusion, by virtue of his education and concentration of practice, the podiatrist detects and provides necessary specialized management of foot-manifest rheumatic disease while cooperating with other members of the medical team in the total care of the patient. The profession of podiatry shares the Commission's vital concern for the welfare of the arthritic patient, offers its full support for the Commission's important undertakings, and requests that it be called upon to contribute in the offensive against arthritis and related diseases.

DONALDSON: Thank you very much. Are there questions?

LEWIS: One question. In your opinion, is the area of podiatry accepted by other doctors, relative to their ability to do a good job in the medical field?



RUBIN: Mrs. Lewis, the profession of podiatry is a relatively young one, and has changed dramatically within the last 20 years. I would say that today our relationship with the general medical community is excellent, and we cooperate with them on a very, very fine basis. That would be my answer; yes.

DONALDSON: Are there other questions? If not, thank you very much, Dr. Rubin. We will now hear from Elaine Seelhorst.

TESTIMONY OF  
F. ELAINE SEELHORST  
PATIENT

SEELHORST: Mr. Chairman and members of this Commission: Thank you for the opportunity to appear here today. I shall bring you some thoughts about arthritis in rural America where my entire life has been spent.

Often arthritis symptoms are tolerated by people and a physician is not seen until the disease is advanced. Since most new developments in the field of arthritis have occurred during the last 10 years or so, most physicians and other health professionals have had little or no training therein. Needless severe crippling, which often occurs, could be alleviated if the public, physicians, and health professionals were better informed.

The most direct way to bring immediate improved care is through continuing education for practicing physicians and health professionals located in rural areas. If at all possible the teaching should occur within the rural setting rather than hundreds of miles away in metropolitan areas, even though the specialists are all located there. This would accomplish three immediate things. First: Physicians in rural areas would fully realize that rheumatic disease is very serious, no longer to be considered aches and pains one must learn to live with and that they are being trained in an all-out effort to help their patients lead more productive lives through improved treatment methods. Second: that patients should be referred when necessary and where the specialists and centers are located. Third: These physicians would quickly learn that a team effort is necessary for the successful rehabilitation of severely disabled persons and that they, too, have a place in the team. Hand-in-hand with continuing education of professionals would be that of the general public via various news media.

Every innovative means at our disposal should be utilized. Specifically, your attention is called to Public Law 93-641 National Health Planning and Resources Development Act of 1974, which is to develop centers for health and technology on a regional basis. Millions have already been spent. There is an established and operational two-way audio-visual interactive TV between Ohio State University School of Medicine and Hospitals, Columbus, Ohio, with four other hospitals in southeastern Ohio. This system could be extended along the Ohio Valley into northern West Virginia, Kentucky, and southern Ohio; thence, to the University of Cincinnati School of Medicine. Indeed, it is the "wave of the future." Someone with vision, imagination, and dedication could set up

marvelous teaching programs on rheumatic disease on all levels. The system seems ideally suited for multifaceted arthritis care and teaching, if we are flexible enough to let it happen. It becomes increasingly so in our area since the Ohio General Assembly passed legislation for the establishment of a College of Osteopathic Medicine at Ohio University in Athens. Also, a degree-program in nursing has just been implemented. Ohio University has long graduated excellent pre-medical and pre-physical therapy students who have become doctors-of-medicine and physical therapists. Since the micro-wave system spans time and space, some alleviation of horrendous transportation problems encountered by arthritis patients in rural areas could be expected.

Another innovation would be mobile units for early detection, screening and diagnosis of those susceptible to rheumatic disease. This would include primary and secondary school students.

Home health care in Athens County is woefully inadequate for those severely afflicted with arthritis. To my knowledge there are no public programs aimed at rehabilitation of arthritis patients. A whole new approach is needed. It is logical to assume the same inadequacy prevails in most other rural areas.

Many people who already have destroyed joints do not know about orthopedic implants which would restore joint function and free them from pain. This knowledge would help keep many of our older citizens out of nursing homes. Public information about orthopedic procedures, as well as various occupational self-help aids, is needed.

People who are contemplating total hip replacement and other such implants need to talk to peers who have had these procedures successfully performed. It is a big decision to make and the most stoical person feels some apprehension. This is not to suggest that the patient be talked into surgery. It does mean informing about things one might expect before and after successful surgery as one has experienced. Video-tape interviews and movies with pre and post operative patients, as well as professionals involved, could be extremely helpful to potential patients and their families. These interviews should follow through successful rehabilitation and return home.

Follow-up for persons with joint implants is a must. As those with implants work, play, and travel in rural areas, the likelihood of traumatic accidents increase dramatically. What are emergency rooms in rural hospitals to do with such victims? Indeed, what is to be done in metropolitan areas? It is urgent that immediate thought be given this problem before there are several million people throughout the country with implants. Now is the time to find solutions to this problem, not ten years from now.

Rheumatic disease is, in my opinion and personal experience, as serious as cancer or heart disease. In 1970 I had a radical mastectomy. The pain following was minor compared to that which I then suffered with RA, continue to and will suffer into the future where I shall spend the rest of my life. Death, in my view, is not the ultimate outrage or



indignity. Invalidism and inability to care for one's most primary body needs qualifies for that dubious distinction.

One can function pain free after a successful radical mastectomy and no one suspects. Not so with RA. The physical pain is forever; deformity, very visible; imprisonment without bars, a reality; mental agony and frustration, total. To add insult to injury no one understands or cares with the exception of a few rare persons.

Persons suffering from severe rheumatic disease, as well as those newly diagnosed, often go through severe trauma psychologically. They desperately need someone to whom they can tell all.

Through the last decade I have learned people will talk to a lay sufferer who treats them as equals. Nothing is held back. This includes such topics as sex, personal appearance, loss of friends and family, and much more. Their credibility and integrity having been shattered by such attitudes and comments as: "It is all in your head." or "Say, just what is wrong with you anyway"? Almost all speak of suicide thoughts at one time or the other. I often wonder how many suicide victims commit this last desperate act because of arthritis. It would be most interesting data because I have heard this desire for relief through death over and over again from other patients during my own hospitalization periods. A common statement being, "I want to die on the operating table if it can't be fixed," usually referring to pain-wracked hips no longer useable. Frankly, that would get a little rough on the surgical team and fortunately does not happen frequently.

The Central Ohio Chapter of the Arthritis Foundation has begun to expand its umbrella into southeastern Ohio counties. When first organized, it served Columbus and Franklin Counties exclusively. The attached map has counties checked which now have organized units, one of the most recent being Athens County where I am a volunteer. Since August of 1974 literature (never before seen by most residents) has been distributed; a public forum teaching about arthritis by specialists from Columbus; and, recently, a seminar for area physicians presented by specialists in the field of rheumatic disease was held in Athens County. There has also been exposure via various media, TV public service spots, cablevision, newspapers, etc. All of this has helped people in our area. Much more needs to be done. Patients are being admitted to clinics in Columbus which are supported in part by the Arthritis Foundation. To my knowledge the Arthritis Foundation is the only source of help available to arthritis patients. The Foundation cannot help with transportation of patients, nor do we envision sufficient funding to do so.

The following are more facts regarding the area covered by the Central Ohio Chapter of the Arthritis Foundation, as well as the tri-state region. There are one million people in Franklin County (Columbus) with one million more in the other 24 counties. There are only eight practicing rheumatologists in the Chapter, all located in Columbus. There are no rheumatologists in all of West Virginia and eastern Kentucky. There is one in Lexington, Kentucky, with several in Cincinnati, Ohio. There is no formal rheumatology program at Ohio State University School of Medicine at this time. The Arthritis Foundation has only three paid staff personnel

located in Columbus to cover the entire 25 counties. All others are volunteers.

These few facts barely begin to point out glaring inadequacies in this field. Certainly our area is not unique in this respect. The need for specialists in every field of arthritis care is so great as to defy description.

Not to be omitted here is my pet -- RESEARCH. The cause of these diseases will be discovered and the cure will surely follow. Let us get on with it so that we will be among the last of mankind to suffer these devastating diseases. The following are three typical stories told by patients and/or their families:

A 14-year-old boy with JRA. For two years a pediatrician diagnosed him as "growing pains." By the time correct diagnosis was made muscle atrophy had occurred. He took off on a friend's motorcycle one evening with no safety gear. His mother was frantic until he returned. This was not typical behavior. His mother asked why he did it. He knew it was wrong. He started crying saying, "Mom, I am afraid I won't be able to ride a motorcycle when I am old enough. I wanted to know what it is like to drive it myself." School authorities paddled him because he and two other boys went to see a friend during school hours. He was badly bruised and marks remained for several weeks. His mother was receiving psychological counseling for domestic problems she could not cope with. She was frantic for a source of help for her son.

In 1954, a schoolteacher was told she probably had RA when she first visited a physician with symptoms. He said, "Lady, I think you have rheumatoid arthritis and if you are smart you will go home and sit in a rocker on your front porch and never do another thing as long as you live." She elected to continue teaching. She took so much aspirin daily to ease the pain that her stomach rebelled with massive hemorrhaging. She apparently did not realize aspirin could have these results. She is on some type of medication now and sees a physician now and then. She needs knee replacements. She was delighted to learn about certain aids and devices she needed.

A man, nearing retirement age, has suffered from severe RA for many years. One can hardly believe the extreme deformity in his hands and feet. Somehow he manages to work although he barely makes it. He has been advised by a rheumatologist to retire. He fell and tore loose all tendons at both knees. An orthopedic surgeon tried to repair the damage. It was a disaster! Both he and his wife are very alarmed at the thought of further surgery advised for his hands, feet, and replacement of the knees. Prior to the accident he did not have a physician. He did nothing about the disease. He does not communicate well with doctors. His wife is a nervous wreck. She can hardly bear the pain she sees him suffering. She said, "What can I do? I love him deformity and all. I shall surely crack up."

There is much more which needs to be said, but there is no time. I can only call a few pressing needs to your attention. The final decision of what is to be done is in your hands.

Thank you.

DONALDSON: Well, thank you very much. I can assure you that the Commission has great empathy for the problems you have raised. We are all aware of them. I am an orthopedic surgeon and I know particularly the one you talk about. Are there other questions?

Since this is the particular part of the Commission I am interested in, would you tell me what you meant when you said that you felt a patient should talk to a lay person in relation to your problems -- would you say as part of the arthritis team, or how did you work that as a structure?

SEELHORST: Yes; I implied that and I do mean that. I do think that somewhere along the line there should be some way for a patient to communicate thoughts. I think it would be very therapeutic if there were someone, say maybe that kind of bridge the gap between the professionals. I am sure that things have been said to me by other persons seriously afflicted with these diseases that they probably won't say to a physician. Possibly they are intimidated, afraid to -- and I speak in particular from the standpoint of what I know best, the area that I come from.

MELICH: Thank you very much.

POLLEY: I would like to ask, do you have adequate medical care in Athens, from your point of view and particularly rheumatologically?

SEELHORST: No; we don't. From the home health care point of view it is woefully inadequate. My own experience, this is so. Now in Columbus, Ohio there are about eight rheumatologists. There about a million people in Columbus. There are a million more in the other 24 or so counties to the southeast of that. Diagnosis -- I have seen it -- we will get people diagnosed by local physicians. They don't know that they have arthritis at all when they are sent to the centers. They didn't even know that there was a place they could go. I have had people call me. By word of mouth they had heard that somewhere I had gotten some help, because I wasn't in a wheelchair and I am no longer in that. They wanted to know, where did I go. People as far away as Pike County, Kentucky calling me on the telephone! This is what happened. This is how I got involved in trying to help with a situation like this.

DONALDSON: Well thank you very much. Our next witness really needs no introduction as far as people involved in the world of rheumatology is concerned, but for the record it is Dr. Daniel McCarty, Chairman of the Department of Medicine, Medical College of Wisconsin. Dan.



TESTIMONY OF  
DANIEL J. MCCARTY, M.D.  
CHAIRMAN, DEPARTMENT OF MEDICINE  
MEDICAL COLLEGE OF WISCONSIN

MCCARTY: Thank you very much Bill. It is a pleasure to have this opportunity to appear before this unique body. I have been chairman of the medical department at the Medical College of Wisconsin for about 18 months. Before that, for 15 years, I was head of a rheumatology section, first at Hahnemann Medical College in Philadelphia; for the 8 years prior to my coming to Milwaukee, I was head of the division of arthritis and metabolic diseases at the University of Chicago. I want to make it perfectly clear at this point that I continue to be active in the care of arthritic patients and teaching and research in arthritis, despite my new position. I would like to make five points.

One: The ultimate goal of a National Arthritis Plan must be improvement of patient care. That must be the overriding priority. How to get there. We must develop the ability to deliver excellent care based on current knowledge, which we are not doing -- I think Dr. Carley spoke to that this morning; and two, develop new knowledge and research that will lead to better understanding of the many types of arthritic diseases and either to their prevention or to improve diagnosis and treatment.

Two: I think it is fair to say that U.S. medical schools have done a very poor job in educating students in the arthritis field relative to many other areas of medicine; for example, heart disease or obstetrics. Very few medical students cannot rattle off a list of various kinds of congenital heart disease, which they will rarely see and never treat; but few residents in medicine, people three or four years beyond this, can intelligently lay hands on a patient with arthritis. I would like to cite the fact that I once performed a piece of research which required opening up the knee joints of 215 anatomical cadavers in four of the five Philadelphia medical schools over a 2 year period. These are anatomical cadavers, and this was after the freshman med students were finished with them. Not one knee had been dissected; not one joint had been dissected. This was very nice for the purposes of our study. However, I could find no hearts, lungs, or kidneys that had not been not dissected exhaustively. I just point out this fact because the neglect of the musculoskeletal system begins very early in medical school education.

Three: Excellent patient care, I think everyone would agree, is best delivered by a team approach with medical people, paramedical people, and surgeons; but all teams require a captain. I believe that the rheumatologist, i.e. an internist with two additional years of intensive training in the field of arthritis, is superbly equipped to captain such a team.

Four: How many rheumatologists are there in the United States and where are they? This is a preprint of an article which is in press in "Arthritis and Rheumatism", a journal close to my heart, since I was its editor for five years--a few years ago. There are roughly 900 such specialists in the United States. As a result of the first two

examinations given for this purpose in 72 and 74, about half of these are diplomates of the American Board of Rheumatology.

Five: How many rheumatologists do we need in the United States? I think this point deserves a lot of study; and my study here is relatively crude. A manpower study conducted by the Arthritis Foundation several years ago in 1972 suggested 4.2 per million population. One rheumatologist per--I am sorry--per hundred thousand population. One per hundred thousand would appear to be a rock bottom figure. Only two states have one per hundred thousand at the present time; that is New Mexico and Massachusetts. The State of Wisconsin needs at least 40 more to reach that rock bottom figure.

My conclusions are as follows: One, that the training of the team captains of the rheumatologists be the first order of priority. Two that the sites of need be pinpointed; that the job descriptions be looked into; and that the facilities needed for the team care be created in these sites of needs. Third, that centers based in teaching hospitals that have meaningful major University affiliation be strengthened to include: 1) a clinical team that serves as a model of efficient and effective patient care and 2) the capacity to perform meaningful research and postgraduate education.

Thank you.

DONALDSON: Thank you very much. Are there questions for Dr. McCarty? Yes.

SHARP: Dr. McCarty, the recent survey of the Professional Education Committee of the Arthritis Foundation has shown that there are 26 medical schools in this country without rheumatic disease divisions or sections. Even in those institutions that have arthritis programs, medical students and house staff rotate through those programs -- only ten percent of the total rotate through those programs. I wonder if you would speak to why this situation exists; is it tolerable; and how can we overcome it?

MCCARTY: Well, I may not have all the answers but I can give you my biases. Number one: Rheumatology is a relatively recent speciality. I think it was growing rapidly until the demise of the training program, the so-called research training programs which were, in fact, training people for practice. The demise of these programs cut the heart out of many of the arthritis programs in the United States. At least it certainly stopped the growth. We are training no more rheumatology specialists now than we did 10 years ago, I don't believe. The reason I site that is because the applications for membership in the American Rheumatism Association are linear; they have not risen sharply.

I think that as a chairman, I can speak to the financial problem in supporting any meaningful critical mass of professionals in a given discipline. In other words, rheumatology is competitive with heart, kidney, gastroenterology, endocrinology, etc. Some of these fields are tremendously lucrative. The American medicine, right now, is based on the ability to earn its way. In other words, the cardiology team and the cardiologist doing open heart surgery means money in the pocket of the



hospital; it means money coming in. Arthritis is not a big money-making operation; it is chronic disease. The people who have arthritis must compete for beds with acutely ill people who are bleeding, and so on; they don't compete well.

The fiscal means to develop a critical mass of specialists within teaching hospitals is severely handicapped. I am doing it because I happen to be chairman and also a rheumatologist and I could not stand to have a department without a good rheumatology division. But most chairmen are not rheumatologists, and they really don't care very deeply. They are pressured from the larger divisions to add more faculty. So, I think that is a major problem--the space and the funds, particularly salary support--also for fellowships. There is no ready source of money for fellows.

DONALDSON: Bill, do you have a question?

BATCHELOR: Dr. McCarty, would you touch particularly on the point that in addition to individuals who have a thorough knowledge as experts in this field, that there is a need.

MCCARTY: I think this point came up earlier today, is there any lack of interest in the field. I think not. I think it was an enormous amount of interest on the part of students and house staff in this area. The interest is spurred, however. There is tremendous amount of interest in our institution at the present time. But, it spurred by a hard core critical mass of people who are dedicated to this area -- being in the medical school -- being represented on the curriculum committee -- representing their views strongly in competition with all the other specialties and generalities of medicine. Medical school is a very competitive environment, as you know.

SHIELDS: Dr. McCarty, knowing the overall problem as well as you do, I was wondering, if you were in control of the money, what would be your first priority in terms of where you would put it?

MCCARTY: If I were the czar of the money, I would make sure that every medical school in the United States had a first rate program. The spin-off from that training program will be enormous you see, because the fellows will train the house staff and the house staff will train the students. You get more bang for the buck by putting the money in there -- more than you will get anywhere else.

The second thing, I think I would put money into programs that essentially have positions that are on a full time -- or they have some limit on the top of their salary. In other words, I don't think that we should simply stimulate private practice. There is nothing wrong with this, but if good teaching is to be done, the teacher has to have time to teach, and not be totally consumed with patient responsibilities. I think certain criteria, as to the development of these programs, has to be worked out -- these guidelines. I would insist that the training of the future consultants be first-rate; that is, on a par with the training of a cardiologist, endocrinologist, or other types of specialists. This means some exposure to research, because if they don't have that, they won't be

able to read the literature. There is no way that they will be able to educate themselves on into their careers.

DONALDSON: Well, thank you very much. I am afraid we must move on. Janet Zahorik.

TESTIMONY OF  
JANET ZAHORIK  
PATIENT

ZAHORIK: Some 16 years ago, I told our family doctor that for the past few months I had been having morning stiffness, swollen hands and feet.

He quickly looked at my swollen fingers and said, "You may have the start of 'a little arthritis'." Then he added, "You are lucky. At least it is a disease you won't die from -- but sometimes you may wish you were dead!."

"Try to rest more," he said, "and take some aspirin whenever you have any pain."

My doctor, at that time, was as informed about arthritis as I was.

Not long after, I thought I certainly was lucky. Things began to go better. I thought my "little arthritis" had just gone away.

Now I know better. My disease was still active, but I had gone into a remission.

For the next few years my arthritis was a kind of on-and-off thing, but I could somehow manage my daily activities.

Then I began to feel, once again, the morning stiffness, pain, and tiredness. Only this time it lasted for longer periods of time, and the pain was becoming more severe. I was having a difficult time trying to keep up with simple everyday things. From my hands and feet, the pain was beginning to travel to my knees, hips, elbows, and shoulders.

With slippered feet and a shuffling walk, I found another doctor. This doctor took x-rays and blood tests. He confirmed I had rheumatoid arthritis and suggested I go to the hospital for a complete joint rest. I know now that would have been the best thing for me to do. But at the time, with three young, lively children, a husband working two jobs, and a good-sized house for me to maintain, I felt it was impossible for me to be away.

Yet, my life was becoming impossible, too. The doctor's parting words to me were: "If something isn't done for you, you will end up in an institution."

I am sure he said this because he wanted me to realize the seriousness of my illness. But my disease still had not been fully explained to me -- no program worked out on how I could cope with it myself.

I went home with devastating visions -- visions of crippled hands and wheelchairs. This was all I knew of arthritis. I knew no one who had rheumatoid arthritis. There was no one to talk to about the feelings and fears I had. Or, would anyone understand them?

I felt completely alone and went home feeling not only physically ill, but emotionally ill as well.

This was my introduction to rheumatoid arthritis.

I have come a long way since that day. I was fortunate in finding an excellent rheumatologist. I have learned about my disease and how to work with it.

This takes away much of the fear associated with a chronic illness.

As an arthritic, my sincerest concern is with the thousands of people in Wisconsin who need our help. We can help many, with patient and family education, thus saving them from those first painful and frightening steps,

I firmly believe, for this to become a reality, we desperately need more funding for:

- (1) patient and family education
- (2) the training of more rheumatologists
- (3) funds-for research
- (4) educational programs for nurses, O.T. and P.T. Departments, who work closely with the patient and need to relate to their fears and frustrations.

All this will take money!

But let us help as many arthritics as we can, and they, in turn, will begin to help themselves and others.

I strongly urge the National Arthritis Commission to help us utilize these programs with appropriate funding!

To give us the chance--to wipe out the Nation's number one crippling disease.

Let's put hope back into the eyes of the already afflicted.

Let's take the desperate fear -- yes, fear -- from the eyes of any man, woman, or child, if ever they should hear these words:



"The results of your tests show you have Rheumatoid Arthritis."

DONALDSON: Thank you very much. Yes.

SHIELDS: I would just like to ask a similar question to a patient that I asked to Dr. McCarty. In terms of -- from your standpoint, if you were in control of the funds, where would you feel your priority would be?

ZAHORIK: Well, naturally, everyone would like a fast cure; but the results from research will be a long-range goal. We all know we need more rheumatologists, but a rheumatologist can't be stamped out in a year or two; so we have another long-range goal. As an arthritic, I want to see an accelerated action plan that would be of service to the patient now; family, patient, and allied health educational programs. These programs would benefit the patient and their families in learning, in adjusting, and learning to cope and just live with the everyday problems of arthritis until we achieve--and we will achieve -- our ultimate goal.

DONALDSON: Obviously you have impressed everybody, including the audience; we thank you for coming here and sharing your thoughts with us. I will now ask Dr. Goldman if he would please come forward.

TESTIMONY OF  
ALLAN L. GOLDMAN, M.D.  
CHAIRMAN, WRMP/WAF SUBCOMMITTEE;  
DIRECTOR, ARTHRITIS PROGRAM, SACRED HEART REHABILITATION HOSPITAL

GOLDMAN: The importance of conservative therapy using a team approach in a controlled environment has been emphasized by Dr. Engleman. Unfortunately, Dr. Engleman also pointed out that this type of care is rarely available in the United States. In major teaching institutions, the isolation of patients with rheumatic diseases for extended periods is not always compatible with the needs of medical education programs. A patient whose disease will be with him the remainder of his life, may have difficulty in finding the emotional support in the traditional teaching institution. While we all recognize the need for education, we must also recognize that the patient's needs cannot be compromised.

Understandably, the patient needs services of skilled physicians and surgeons, but writing prescriptions or replacing a joint will not permit the factory worker to continue at the production line; the mother to care for her children; or the little leaguer to be like other little leaguers. The patient will not be the only one affected. Family roles will have to be changed and priorities re-established. This is the management of chronic disease and this is the challenge that the Commission must face.

While research and education must have continued support, more attention must now be paid to delivery of health care. This means not just diagnosis and treatment, but rehabilitation and readjustment. More rheumatologists are needed, particularly in Wisconsin, which is a physician poor State, but many people will suffer if we wait until enough rheumatologists are trained to care for the arthritics of the State.

I would like to propose that the National Arthritis Act provide funds for the development of rheumatic disease units throughout the State that would serve as regional referral centers. They would have the capabilities to handle all aspects of care, in addition to their own areas of expertise, i.e., rehabilitation, juvenile rheumatoid arthritis, rural outreach programs and training of allied health personnel, etc. These units would be integrated with each other and with the medical schools whose standardization of care, data collection, cooperative studies and clinical evaluation.

The long-term benefits both for the patient and society for specialized care must also be emphasized to the insurance carriers. During the past year there is evidence that they are reluctant to pay for "change of milieu" treatment. This is particularly true of Government programs. The purpose of rheumatic disease units could be defeated unless this trend is checked.

At present, the major thrust of rheumatology is aimed at inflammatory disease, yet the biggest single cause of disability in the United States is osteoarthritis. It is estimated that 20 percent of all patients coming to physicians' offices are there because of musculoskeletal complaints; and the majority of these are from non-inflammatory conditions. If for no other reasons than the cost to society, more research should be directed toward these areas.

Mr. Chairman, Members of the Commission, thank you for the opportunity to express my thoughts.

DONALDSON: Thank you. Are there questions? Yes, Bill.

BATCHELOR: (Inaudible.)

GOLDMAN: Yes; right now the Regional Medical Program is working with the Arthritis Foundation, the rheumatologists, and other personnel of the State to develop a comprehensive health care program for the State.

BATCHELOR: I just wondered what extension solved the effort through this program as something on which you (inaudible).

GOLDMAN: If it was not for this program, these people would not be meeting together; that is the number one thing. The fact that is -- you are talking about the Arthritis Act?

BATCHELOR: I hold reference here to the RMP, I am not sure whether you can identify from the outreach programs that are needed.

GOLDMAN: Yes; I have. I have been identified with basically coordinating many of the different things which we have, and all the RMP projects have been aimed at bringing more coordination between the institutions and also expanding care. So this is the type of thing which -- I think -- which we should direct our attentions at. I think this should not be independent, however, of the medical education and research program. What I would suggest is that we attempt to integrate the two. You know, what we have now is two parallel systems; the university systems

and then the health care delivery systems. And certainly I think both could be strengthened.

SHIELDS: Where do you see the initiative for establishing such regional distributions coming from?

GOLDMAN: Well, this is what I meant when we talked about the National Arthritis Act. Everybody talks that it is a good idea to do, but until somebody heard there was money available, the people from the different institutions didn't really get together. I might also add that the two institutions where I am based both have rheumatic disease units. We talked for a long time that this was the way to treat people, but until RMP funds were available to say here is a project...But the project cannot be done unless patients are on one ward. We have a rheumatic disease unit; those units are now established. The projects are winding down, but nobody would dare disassemble the units. So this is the initiative; something that goes on after the project ends.

SHIELDS: Along the same lines, how many rheumatic disease units of this type are there in Wisconsin, in this network? What are some of the more deprived areas even now in Wisconsin; and how do you start a new unit?

GOLDMAN: Okay, first we have -- I am going to let that go a little bit to John Hutchins who is from Wisconsin WRMP, and I may even have a chart to show you where they are geographically around the State. We have them -- I will let him comment on that. The impetus must come from the people who are capable of delivering the care. In other words, people talk about it, but unless you have the people capable of delivering the care there, you can't get it going. Once you have the people who can show, in a given area, that this is the way to treat people, the patient demand is fantastic. I mean, every rheumatologist in this State has people waiting in line. You know, we are not like some other areas of the country out looking for business. We are trying to figure out how we can better handle it. So, showing that there is a way of treating these people immediately creates the need. Particularly though, I would say the northeast region of this State is particularly lacking. I would also add that I would hope that the plan, the Arthritis Act, would recognize the vast differences among the states and what is necessary here in Wisconsin is not what is necessary in New England or someplace else.

SHIELDS: Let me ask just one more quick question. Your practicing rheumatologist in the health manpower survey showed that rheumatologists in the country were poorly utilized, and their skills really weren't being taken advantage of through difficulties and referral and what not. Is this true in your own case, and what are the problems in you performing your best services?

GOLDMAN: I don't think that is really true in my particular case, but we have put an awful lot of administration effort in getting a system up in which we can expand our potential by the use of allied health personnel both within the hospital and without the hospital. Wisconsin, being a physician poor State, there is no problem with physicians wanting to refer



to rheumatologists. Occasionally there is. Whereas, when you have too many physicians they might--well, in here there is no problem.

DONALDSON: Thank you very much. I would ask Drs. Pachman and McDuffie to join Dr. Gore at the table, if you would please. While they are coming up, a number of the members of the Commission thought that I should make a brief statement concerning the dollars. The National Arthritis Act does have in part of its provisions suggested dollar amounts for implementation of the eventual programs to be developed and recommended back to Congress. However, in fact this does not (inaudible).

TESTIMONY OF  
DONALD R. GORE, M.D.  
ORTHOPEDIC SURGEON

GORE: I am an orthopedic surgeon who has been in the private practice of medicine for seven! years. I practice in Sheboygan, Wisconsin, which is a community of just under 50,000 people and with a drawing area of approximately 100,000. Although the majority of my professional time is spent in Sheboygan, I contribute one day a week teaching orthopedic surgery to residents in training at the Medical College of Wisconsin. In addition, I have been actively involved in research pertaining to the evaluation of total joint replacement. This has been conducted at the Kinesiology Laboratory at Wood Veterans Administration Hospital, Wood, Wisconsin.

From these vantage points it appears to me that there are four areas of education that need immediate remedial measures. These are:

- (1) Physician Education
- (2) Paramedical Education
- (3) Patient Education
- (4) Public Education

I would like to consider each of these separately.

Primary care physicians in smaller and moderate sized communities regularly see large numbers of patients with complaints of an arthritic nature. Most of these patients require only a skillful examination, followed by a thorough explanation of their condition and reassurance that their problems are not serious. A few require extensive and expensive evaluation and life-long treatment. Appropriate patient selection depends on a thorough understanding of the arthritic diseases. This knowledge was not available when older physicians were trained, but, unfortunately, though available now, is usually not taught in medical schools or the usual postgraduate training programs.

Paramedical personnel are invaluable in the everyday management of disabilities caused by arthritis. Simple instructions on preventing deformities and techniques to increase physical productivity help an



arthritic patient retain his or her place in productive society. Many times, though, these paramedical personnel spend their time administering useless and expensive modalities which contribute nothing to overall well-being of the patient.

Patients' understanding of their problems is probably the most important single factor in maintaining productivity and avoiding unnecessary and sometimes dangerous treatment. Some patients believe the term arthritis is synonymous with life-long total disability. These people spend their lives looking for their pot of gold in social agencies.

Learning to live with our problems is basic to human survival, but some of us, and particularly those disabled by arthritis need more outside assistance than others. The well educated, white collar worker or professional with a little resourcefulness can usually adapt to his or her disabilities. The factory worker or laborer is much more dependent on his employer. Unfortunately, unrealistic workmen's compensation laws have made hiring of disabled persons simply too expensive.

The solution to the above problems are education of physician, paramedical personnel, patients, and the public as a whole. This type of education must emanate from medical centers that provide initial education to medical personnel, but also who effectively disseminate information to those in smaller communities. These goals can only be accomplished when funds are made available to be used primarily for teaching and not tied to the strings of an elaborate research program.

Thank you.

DONALDSON: Thank you. Are there questions from the Commission members?

I think this is a message that we have heard repeatedly as we have gone around the country, and it is certainly one that we have no problem dealing with as a Commission. You can be assured that it will be a part of our recommendations.

GORE: Thank you very much.

DONALDSON: Dr. Pachman.

TESTIMONY OF  
LAUREN M. PACHMAN, M.D.  
HEAD OF IMMUNOLOGY  
CHILDREN'S MEMORIAL HOSPITAL, CHICAGO

PACHMAN: I am a Board Certified Pediatric Immunologist. I am the head of the Division of Immunology at Children's Memorial Hospital in Chicago. It is the purpose of this testimony to document some of the existing medical resources in Illinois and in the Chicago region, and to discuss the problems particular to the pediatric population.

There are seven major medical programs in the Chicago area and representatives from each of these programs are on the Medical and

Scientific Committee of the Illinois Chapter of the Arthritis Foundation. (Appendix I lists the members of this Committee for the year 1974-75 and Appendix II outlines the agenda for that year.) This development and use of regional resources in a coordinated fashion is in accord with the National Arthritis Act of 1974. Financial aid is available from the Division of Services for Crippled Children for any child with a connective tissue disease who financially qualifies. The DSCC operates a network of clinics (Appendix III and IV) in various sections of Illinois which act as intake stations which then send children on to the appropriate speciality clinic.

In the Chicago area alone, an estimated 20-30,000 adults have rheumatoid arthritis. There are 3,500,000 children under the age of 16 in Illinois and 12,000 of these may have JRA. Who provides care to this active patient population? In Illinois, rheumatologists number only 20, with all but three based in the Chicago area; and of the 20, there are only three who are Board Certified in Pediatrics and limit their practice to Rheumatology-Immunology. If all the 12,000 children in Illinois were identified, 15 to 20 pediatrically trained individuals working full time would be needed to deliver the current level of medical practice. To illustrate further with data derived from Children's Memorial Hospital in the year 1974, 224 patients made a total of 780 visits with myself as the senior responsible physician. Each visit required a minimum of 20 to 30 minutes in which the child was evaluated by the various services (medical, orthopedic, and physical therapy). Referrals of four to eight new cases per week are routine, either on an inpatient or outpatient basis. In 1974, 25 children with JRA were hospitalized, 11 with dermatomyositis, 26 with systemic lupus, and 15 with acute rheumatic fever, all at Children's Memorial. It is difficult to assess the prevalence of rheumatoid disease in childhood because the specific disease syndromes are not well characterized either clinically or medically. There is increasing evidence that rheumatoid arthritis has a different clinical course in children than in adults; research about the disease process in children has been slow to develop and data lags far behind, even that which is known for adults. Metabolically, children are not "little adults." Moreover, information is scarce concerning the effects of drugs, widely used in adults, on children.

Patty is 12 years old and I asked her to come to illustrate some of the simple questions for which we have yet to find answers. What is the basis of her disease activity? She and many other females of childbearing age are given gold shots -- how long should they be given, how does it affect the potential fetus, what other drugs can be used? Until basic knowledge about the disease process is obtained, the therapeutic approach must be, at best, stop-gap.

The final conclusions are evident. There is an existing network for communication and delivery of care in the State of Illinois; some financial coverage is available for children, but it is often inadequate. More physicians and medical support service should be trained in the area of both pediatric and adult rheumatology to deliver the existing body of knowledge. Our knowledge of pediatric connective tissue diseases must be effectively extended to identify and treat children and prevent these children from becoming irrevocably disabled.



DONALDSON: Thank you very much. I don't think you have any trouble impressing us about the care of children, particularly when you bring one like that along. Are there questions? If not I think you have made your case for the child very adequately. We thank you for it. Now, Dr. McDuffie.

TESTIMONY OF  
FREDERIC C. McDUFFIE, M.D.  
RHEUMATOLOGY RESEARCH LABORATORY  
MAYO CLINIC

McDUFFIE: I am testifying before the Commission as a representative of the Minnesota Chapter of the Arthritis Foundation. My background is that I am a physician who received training in clinical rheumatology and research in arthritis in Boston and New York in the 1950's and then spent 8 years as director of Rheumatology at the University of Mississippi Medical School. During this period I ran an arthritis clinic and an active private practice of rheumatology. For the past 10 years I have been at the Mayo Foundation engaged almost full time in laboratory research in arthritis and immunology, but I have maintained active contact with clinical activities in arthritis at that institution. At Mississippi I played a role in the formation of a chapter of the Arthritis Foundation and served for a while as its president. In Minnesota, I have also been involved in the affairs of the State Chapter and am currently chairman of its Medical and Scientific Committee.

I wish to address my testimony to two major issues. The first concerns support of research and the second one expert care of patients with arthritis.

I am sure the Commission has heard repeatedly about our lack of knowledge concerning the cause of most forms of arthritis and the current unsatisfactory nature of much of our treatment. We have an overwhelming need to gain better understanding about diseases of the joints, particularly rheumatoid arthritis and osteoarthritis, the major long-term crippers. I think that in the long run money spent for research will provide more benefit for patients with arthritis than almost any other form of expenditure. Naturally, I do have some personal interest in this question because of my own involvement in arthritis research, but I believe my views which are based on personal experience may help the Commission in establishing its priorities and goals. I want to urge the Commission to recommend support of research in arthritis on a broad scale. It is impossible to know at the present time exactly what scientific fields or exactly what laboratory's results are going to provide findings which will have an important impact on the solution to the arthritis problems. Overemphasis on apparent relevance to arthritis in the support of research will constitute a grave mistake. A major advance in our understanding of arthritis in the last two or three years has been the recognition of a close association between a form of arthritis of the spine (ankylosing spondylitis) and the presence of certain genetic markers on lymphocytes and other cells. This work, carried out both in England and in California, has identified a hereditary link between the development of this form of arthritis and a so-called antigen on cells

which is responsible, among other things, for rejection of kidney transplants. I suspect that very little of the financial support for basic research on these antigens was provided by grants recommended by the Arthritis Study Sections of the National Institutes of Arthritis, Metabolism and Digestive Diseases. Much of the support for this research came from those interested in kidney transplantation and in blood transfusion because of the obvious connection between these antigens and these two fields. Nonetheless, the benefit for arthritis research has been enormous. If a single cause for rheumatoid arthritis is ever found it will be possible, looking back, to see that this discovery has been based on a gradual accumulation of basic knowledge from many different fields, and unless every link in that chain is present, the final solution cannot be attained. I believe that the Commission should recommend that the National Institute of Arthritis, Metabolism and Digestive Diseases identify certain areas of basic science research that are likely to have a very strong impact on arthritis and support basic research projects in these areas on the basis of quality, regardless of its apparent relevance to arthritis at the present moment. Such possible areas would be:

- (1) Mechanisms of inflammation, including chemistry and physiology of so-called mediators -- proteins and smaller molecules that play important functions in the attraction of white cells and platelets to areas of inflammation, phagocytosis of particles and release of enzymes that may cause damage to tissues.
- (2) Virology with particular emphasis on the study of viruses which do not express themselves directly, but incorporate themselves into the genetic makeup of cells, so as to alter their metabolism and the production of cell markers.
- (3) Molecular genetics, with particular emphasis on the coding of cell surface markers such as the HLA and MLC antigens.
- (4) Control of antibody synthesis and the interrelationship of different classes of lymphocytes involved in immunity.
- (5) Mechanisms of tissue damage by immune complexes and the complement system of proteins.
- (6) Cell membrane structure.

All of these important fields and others that may be suggested represent major interests of other research institutes at NIH. I believe that those responsible for administration of funds for arthritis research should attempt to identify outstanding research proposals in these fields and make sure they are supported. In particular, an effort should be made to identify and support research proposals which tend to "fall between the cracks," in other words fail to receive support not on the basis of excellence, but because they do not fit clearly into any single well-defined clinical or scientific area. Though I believe major support



should go to basic science areas likely to provide the foundation for productive arthritis research, I also believe that some funds should be spent on more clinically related problems, in particular objective assessment of current therapeutic measures. In particular, I would single out modalities of physical therapy which are very widely used in the treatment of various forms of arthritis, but for which we really have little good objective information as to what procedures make a difference to the patient and what procedures are essentially worthless. If we are going to accelerate our program for the care of arthritics it is obviously crucial to spend our funds on forms of therapy that are really going to be worthwhile for patients.

The second point I would like to comment on to the Commission concerns enhancement of professional skill in the care of patients with arthritis. For many years those of us in academic rheumatology have constantly emphasized the need to train more board-certified or board-eligible rheumatologists. However, it is now very clear that because of the magnitude of the arthritis problem, it is never going to be possible to train enough experts to take care of all the patients with rheumatic diseases. Furthermore, the current political and social climate of the country is such that major emphasis is now being placed on the production of general physicians as opposed to specialists. I think all of us in the arthritis field recognize that most physicians do not understand the care of arthritis very well and do not really have a keen interest in taking care of people with this kind of chronic disease. I support the development of centers of excellence in arthritis, but I do not believe that these can ever be responsible for the primary care of the vast majority of arthritics in the United States. These centers should serve as models, but that in order to make these models effective, we are going to have to develop a new kind of practitioner who will assume the major responsibility for the care of patients with arthritis. Such physicians will be general practitioners, general internists, and, to a lesser extent, pediatricians, physiatrists and orthopedists. They should be identified by a special interest in arthritis which may, however, not be their major field. Arrangements should be made for such physicians to receive intensive training for short periods of time in an arthritis center in their geographic region, perhaps six to eight weeks at repeated intervals every two to three years should be sufficient. Arrangements, of course, must be made for coverage of the medical practices of these individuals while they take such short-term training as well as for some financial compensation so that they will not suffer serious loss of income during the training period. This training should consist not only of formal teaching by lectures, films, and demonstrations, but also considerable opportunity to take care of arthritic patients in the hospital and the office under the close supervision of experts. After completing such training, these individuals should maintain close ties with the center by arrangements which can perhaps best be left to the ingenuity of the centers to develop. In their own communities, these individuals should be able to achieve the status of experts in arthritis and not only to direct the care of their own arthritic patients, but to assist and advise in the care of patients of other physicians. They also, of course, will be very useful members of voluntary and government organizations committed to patient education and other social and political aspects of arthritis. I believe that it is very important for



the Commission to come up with a plan to upgrade the care of patients with arthritis, a plan that is more innovative and at the same time more realistic than simply recommending training more subspecialists in rheumatology. I don't deny we need more specialists primarily to train other physicians and to act as key members of arthritis centers. I believe that a program of developing semi-experts will be more effective and perhaps less costly than simply training more subspecialists.

There are many other important issues for the Commission to consider, but I wished to focus on these two. I believe the success of the Commission is going to depend in large part in coming up with recommendations that are new but solidly integrated into the general pattern of medical practice and research in this country. I think it is very important to avoid making some of the mistakes that have characterized the cancer effort which, in my opinion, has become split off from the overall pattern of medical care and research. It has put far too much emphasis on drug therapy with sacrifice of emphasis on research. I appreciate the willingness of the Commission to listen to this and other testimony. You have a hard job ahead of you in coming up with a plan that will gain the support of patients, physicians, scientists and others concerned with the arthritis problem, as well as the necessary backing from the Congress and the administration that will make it a reality.

DONALDSON: Thank you very much. Are there any questions? Yes, Mrs. Melich.

MELICH: I was Interested in what you said about the six to eight week training periods for doctors. Are you saying that you think that the people that need training in arthritis would come to the centers that are set up by the National Arthritis Act or are you saying the existing medical schools or whatever they have could be implemented to contain classes in retraining these doctors in arthritis?

MCDUFFIE: I guess I don't quite understand the question. Do you mean -- are you asking whether or not the present centers could do this kind of a job and that we need more centers?

MELICH: I am asking you both. Do you think that we could use existing centers with additional funds used to implement what they have; and then also, the new centers that would be set up by the Arthritis (inaudible).

MCDUFFIE: I think the answer must be both. I am sure that when such centers, if money becomes available, that existing centers will be strengthened--that we already have. On the other hand, of course, it has been pointed out there are areas where we don't have centers where new ones will have to be developed. But I think we have to start to build on what we have got at the moment. It has been pointed out we just don't have the trained people to staff a lot of new centers.

MELICH: Do you think that is long enough time, six to eight weeks?

MCDUFFIE: Well, I guess I am a little bit arbitrary about the time. I think one has to be practical about how much time an individual can be away from a practice and exactly how much expertise a person is going to

develop. I think that currently we have emphasized that most of our postgraduate training of physicians is based on lectures and courses. An individual will come in for a day or so and listen to a lot of lectures and they go back. But I think that such training is relatively superficial, and unless the student can come in and actually take care of patients and see specific problems in arthritis with the physicians in the center, discuss these cases, go over them in detail, learn how to take proper histories, learn how to use the laboratory tests and so forth, that he is not going to be very effective. Eight weeks, you know, we would like it to be much longer. I just chose this as perhaps a time at which one could at least develop something, at least be able to recognize arthritis, and to at least learn to work with the people in the center. Maybe this is the important thing, so that when difficult problems come up they can work back with the center people and communicate with them. I think refresher periods, you know, every couple of years or so would obviously be good to do. I think centers are fine, but I think the Commission has got to think, how are the benefits of these centers going to have an impact on the smaller towns.

DONALDSON: Yes, Gordon.

SHARP: Dr. McDuffie, I think that the coming into the centers is an excellent idea, but I think that we must be realistic, that perhaps there will not be a very large percentage of physicians who will be able to leave their practice for that length of time; so that some kind of outreach from the centers also is necessary. What, in your estimation, are some of the more effective types of going out from the centers to reach the physicians and/or other professionals there in their own communities?

MCDUFFIE: Well of course, lecture programs have their limitations as I have pointed out, and I am sure you would agree with this. Certainly one area -- and one area that we have done it in, Rochester -- is of course, development of consultation programs where individuals will go from the center to the smaller town, let us say once a month -- to the hospital. At that time patients with rheumatic disease or arthritis problems would be brought in and the specialists -- the rheumatologists will see the patient, examine the patient, talk to the physicians from the community, who will be there taking care of the patient; and they will actually be able to focus on the patient's specific problem. Then if it becomes apparent that the patient needs to come to the center for care, this can be arranged. If not the patient can have the benefit of that consultation and the physician in charge will learn something from that. I think that is a fairly effective program, but again, I don't think it would be as effective as bringing them in. Although I certainly agree with you that the practical difficulties may be very great a lot of it, I think, is financial. Possibly the Arthritis Commission might be able to overcome some of the financial blocks.

SHARP: Well I think that this is the problem. Many of the centers who would like to go out and carry on these consultation clinics and what not are not strong enough in manpower to carry this on. So, although I agree with you that we can't generate enough rheumatologists to care for every arthritis patient in the country, it would still seem to me that there is



a need to generate more rheumatologic professionals if we are to carry on any of these outside consultative activities.

MCDUFFIE: I don't deny that at all. I simply wanted to emphasize a different aspect. I thought that other point had been well made by the other witnesses. I don't disagree with them at all.

SHIELDS: One comment, I think that in reference to a lot of the treatment, one of the concerns as a physical therapist that I have in treating patients is that it is so easy to addict people to a physical therapy department because often times what you do helps a person and they feel better, but in reality I have made that person a more dependent person on my ultra-sound machine, my Hubbard tank, my diathermia, etc. I recognize the problem and the need to train allied health people how to take care of chronic disease problems versus the types of problems they have been trained to do. You alluded to the fact that more research is needed in the area of rehabilitation. Would you care to comment as to why it is not being done now; is it the need of money; why aren't we doing that kind of research?

MCDUFFIE: The only thing I can think of is that the reason may be that the kind of evaluation we need requires the close cooperation of the rheumatologist, let us say, and the physical therapist and the person in physical medicine. In other words, this kind of research needs to be carried out by that particular team. Research in general tends to be initiated by an individual working for himself, so that, I think, this is perhaps one aspect. For many years orthopedic surgeons, of course, tended to be rather lax in their evaluation of the procedures that they were carrying out. In the last few years, I think we have seen a marked change that orthopedic surgeons have recongized that the same kind of hard criteria controls and so forth in evaluating the results of surgery need to be used as we use in the use of drugs. I think it is just a question of time until this gets into physical medicine, but you know, such things as casting, splinting...Does splinting of the hand or wrist, really prevent deformity down the line? I don't think we know. If you ask a rheumatologist and people in physical medicine you will find a lot of disagreement, but you won't hear many of them quoting figures that really support their contentions on one side or another. They will simply quote their own personal biased professional experience. And of course the psychology, and I think this has been emphasized by members of the Commission, the psychological aspects of therapy are very important. I don't deny that. I think they are very important, but I think we must recognize and identify what is psychological, on what basis it is psychological, and on what basis it effects; the disease and let's dissect out those elements so that we really know what we are doing. We just don't know what we are doing right now, I think.

DONALDSON: Thank you very much. I am afraid we must move on. I would ask Ray Hulce, John Hutchins and Werner Schafer to come to the table. Before you leave Janet, I want to thank her for particularly being here. I only hope that in a very short period of time we have better answers for people like her. Mr. Hulce.

TESTIMONY OF  
RAY HULCE  
VICE PRESIDENT, FORD MOTOR COMPANY;  
CHAIRMAN, MICHIGAN CHAPTER, THE ARTHRITIS FOUNDATION

HULCE: I am an active arthritis volunteer in the State of Michigan, as Chairman of the Michigan Chapter, Arthritis Foundation; regionally, as Midwest Regional Director and at the National level as a Director and member of the Executive Committee of the National Arthritis Foundation. I serve as a citizen advocate for the cause Arthritis. However, as an executive with the Ford Motor Company in Michigan, I wish to speak today of the impact of arthritis and rheumatic disease on industry.

The committee members already know the economic burdens of arthritis on the society are staggering. When we speak of the impact on industry, we are talking not only of the nation's number onecrippler, but of a major cause for losing days at work. We are talking of 14 million lost working days, 4.7 billion dollars lost in wages and 995 million dollars lost in income taxes.

Arthritis is particularly critical to an employer since it is likely to strike in the productive years. Not only do we experience absenteeism and lose workers to pain or rehabilitation, but we feel the impact of what is called the "Ripple Effect" which means need to train replacement workers; need to retrain the arthritis-afflicted worker if that is possible; must retool or retrain, pay higher group insurance premiums; and pay more workers' compensation or unemployment insurance.

For an afflicted employee to successfully cooperate with a course of treatment, he must feel some confidence about the outcome. For most, this means knowing that he can return to his present job or one with similar responsibility. While the patient may be confident about his physician's ability to treat arthritis, he doubts that the doctor is aware of what movements are necessary on the job. He is uneasy: Will he really be able to go back to work?

Thus, a team approach with active employer involvement is vital. A rehabilitation specialist must be aware of the job tasks required. The employer must be prepared to maintain the present job or prepare a new one which can be successfully handled by the arthritic. The physician must communicate a quite complicated diagnosis to everyone involved, so that the effect of arthritis and work effort on every muscle, joint and tendon can be considered in job design. There is an absolute need for an active ongoing training and education program for employers and rehabilitation personnel to be aware of the very complex effects of arthritis and be informed about the prognosis and possible course of the arthritis in each case.

The unions have an active concern for the well-being of workers. It is only a matter of time before employers will be urged to explore those tasks which aggravate a condition as prevalent as arthritis. Many employers today are already willing to do what is necessary to retain an arthritic employee, since the employee is likely to be diagnosed as arthritic after his skills and experience have become valuable to the



firm. Both labor and management need to know what can be done and the tools for a cooperative approach must be made available to them.

We suggest promoting the use of the forthcoming comprehensive arthritis centers as definitive determination points of the existence and degree of arthritic disability and sponsor of education and training for company and union personnel. This work, made available to both public and private entities, could become the greatest guarantee of properly and appropriately spent monies for treatment and rehabilitative services -- we ask that help.

I cannot add to the eloquence of those who have pleaded for more research funds to be spent in the future. I agree that this is the major priority in dealing with arthritis.

But there are a number of things which we must do now to keep arthritics in the labor force. An active preventive health care program can help employees. Patient teaching through the use of visual aids, movies, and dietary and drug counseling is of great value to employees. Industry management can act as a resource to employees, making referrals and directing employees to seek appropriate medical care.

More funds must be spent to train vocational rehabilitation people in working with arthritis -- it is not as simple as working with an amputee.

More rheumatologists must be trained, and more information must be given to the family physician and the industrial physician to help them find and aid persons developing arthritis, particularly in the working years.

More work place design and motion study personnel must be involved, as they are at Ford, in developing work patterns suited to persons with limitations from arthritis, redesigning jobs for people who have developed arthritis, and pinpointing jobs which may aggravate or eventually produce arthritis. Lastly, more of the money given to research in the area of arthritis and screening should go to developing rehabilitation and treatment teams and programs for encouraging arthritics to maintain their place in the work force. We believe the Comprehensive Arthritis Center should be charged with this responsibility as a major ongoing objective.

This team approach, beginning the moment arthritis is diagnosed, has proved itself. Studies have shown that the arthritic can be placed in a new job, once the employer is shown how to use him best. The employed arthritic typically loses no more working days to illness than other employees, once the job has been tailored to their capabilities. I have seen it work, and I know that with increased understanding and training for all parts of the team, the arthritic can maintain his economic self-confidence and the employer can retain an effective employee.

Thank you.

DONALDSON: Thank you, and I know that it is gratifying to the members of the Commission to know of industry's interest in our problem. Are there questions?

BATCHELOR: Is there any information available -- can you tell us anything about the efforts (inaudible) industry, this is an area where the Commission is eager to learn and there are opportunities (inaudible).

HULCE: In our industry, and I can speak generally for the automotive industry, we expend a great deal of time on tailoring the work jobs to be easy and nonfatiguing to perform. We also have persons who are specially trained to work with employees who become in some way disabled -- to develop a job that would be suitable to them. We don't extinguish arthritis as a speciality problem. If a man has a bad back, we know he has got a bad back but we don't get down into arthritis and...However, the same is true of restricted motion and movements. But as in all cases, the people that are doing this work are a marching parade. They get promoted, they go on to other things. Because you made the speech last week, this week there is a new bunch of people marching by. So I feel that a organized, professionally prepared program of continual ongoing training is essential; to take the best features that you would find and make sure they are done throughout industry.

VOICE: You alluded to the fact that some studies have been done showing the fact that arthritic patient can be placed. I think that this would be most helpful -- of any studies that you are aware of that have been done --. If they could be made available. I think this is going to be needed to impress Congress.

HULCE: I will make that effort to pull them together.

MELICH: We are aware that there are several industries that are taking advantage of the skills of people that have had arthritis and have suddenly become to the point where they cannot do anything in the actual factory or wherever, and so they have set up rehabilitative programs where they can do work within their homes. Do you have such a thing there?

HULCE: No we do not. We have a parallel kind of program, however that you might be interested in. There are private employers who we encourage to start businesses which employ the handicapped in such work as packing parts for shipment to dealers. We make an extraordinary effort to work with them, both in channeling our work to them and in being reasonable about the business terms so that they can perform this effort; and we have found that kind of a solution workable.

DONALDSON: Thank you very much, Mr. Hulce. We will ask John Hutchins now if he will speak to us.

TESTIMONY OF  
JOHN HUTCHINS  
PLANNING DIRECTOR, WISCONSIN REGIONAL MEDICAL PROGRAM  
AND  
OWEN LEVIN  
PROJECT ASSOCIATE, WISCONSIN REGIONAL MEDICAL PROGRAM

HUTCHINS: Like most Regional Medical Programs and Comprehensive Planning Agencies, Wisconsin RMP is concerned with transition to the new health planning and development structure mandated by P.L. 93-641. One of the major problems with P.L. 93-641 from our point of view is that it inadequately provides for the development of statewide health care resources. Under the new law, health care planning and development will be on an area basis (e.g., Wisconsin will have six areawide health systems agencies and moreover there will be a 1 - 2 year hiatus in funding even so). Therefore, WRMP has decided that one of its major missions during the transition is the development of statewide health care programs. The testimony given today should make it clear why arthritis should be considered a priority program.

Within this context and especially with the passage of the National Arthritis Act of 1974 and the Regional Medical Program experience in funding Arthritis Initiative Projects, Wisconsin Regional Medical Program began considering the potential of pulling together a consortium of interests in the area of rheumatic diseases. This consortium was conceived as a nucleus of academic, clinical, and public interest that could merge Regional Medical Program goals with those of the arthritis care provider and public interests.

Of particular interest to Regional Medical Program are the delivery of appropriate care in a statewide program -- especially in non-urban Wisconsin. Also of concern are the innovative and cost-effective use of highly trained providers, and the most effective use of scarce resources.

It is the aim of Wisconsin Regional Medical Program, through this consortium, to assess unmet needs, to pull together current resources in a systemically designed plan for cooperation, and to pursue efforts to bring in new resources and better use of that which presently exists.

The consortium will be carrying on a number of functions under Wisconsin Regional Medical Program auspices: statewide survey, outreach consultation team visits, continuing education conferences, and learning experiences for students. The consortium is building a program that will be exemplary of what a diverse group of interests can do in this vital area. As such, this consortium will prepare itself to become grantee to future outside funding and coordinator for arthritis programs that are only now on the drawing board.

The exact nature of the consortium is, at this time, indeterminate. Membership will consist of the Wisconsin Chapter of the Arthritis Foundation, the State's two medical schools through their rheumatology sections, and the current rheumatic disease resources in State agencies, hospitals and the clinics around the State. The consortium will be



established as an entity, though it is anticipated that existing facilities will be utilized without exception.

The advisory subcommittee to the Medical and Scientific Committee of the Wisconsin Arthritis Foundation has been considering plans for structuring this Comprehensive Arthritis Center. Wisconsin Regional Medical program Arthritis Initiative Projects and staff activities have been geared to the development of an integrated program that will interface with and be superseded by Federal or outside funding at the end of this fiscal year.

It is our intent to involve the whole State, to increase public awareness, to make maximum use of scarce resources, to complement, supplement or increase these scarce resources, and to maintain an active role in the area of rheumatic diseases for Wisconsin.

Attached please find a functional schematic diagram of the Comprehensive Arthritis Center as described in the National Arthritis Act. In parentheses beneath each function, you will note present or planned WRMP Arthritis Initiative Projects. These will be further integrated into non-WRMP funded efforts and systematically analyzed for interfaces and necessary infrastructure to assure that all components hang together and that output is maximized while cost is minimized.

Interest and cooperation is high. The Commission is urged to acknowledge in the National Arthritis Plan what states with limited resources and large distances can do to pull together their resources into consortia to deliver more and better rheumatic disease care. Provision should be made to enable and facilitate the efforts of states without large, already established centers to synergistically combine scarce resources.

Thank you.

DONALDSON: We have time for just a couple brief questions.

BATCHELOR: One feature of the RMP programs that can be of great help to the work of the Commission in its evaluation effort--is the Wisconsin program engaged in any family effort, the results of which might be available to us?

LEVIN: Well, I think like most RMPs we evaluate all our programs. Again, it is the extent of the resources that are remaining in the time. We have about half the staff we had two years ago, and within that context we will be happy to cooperate.

DONALDSON: If there are no other question, thank you very much. Werner Schaefer. And I would ask Sam Geller and Wilfred de St. Aubin to join him at the table please. Please go right ahead, sir.



TESTIMONY OF  
WERNER J. SCHAEFER  
PRESIDENT, MILWAUKEE COUNTY LABOR COUNCIL  
AFL-CIO

SCHAEFER: My name is Werner J. Schaefer, I am president of the Milwaukee County Labor Council, AF of L - CIO, and I am immediate past Chairman of the Board of United Community Services of Greater Milwaukee.

While I have a personal concern for improved treatment of arthritis, my overriding motivation is for the thousands of working people in Wisconsin who must deal with the pain and crippling of arthritis on a daily basis.

The Commission knows the statistics of lost dollars and human resources caused by arthritis. We only wish to note that Wisconsin's share of that loss is \$75 million each year...most of which comes out of the pockets of working people. I firmly believe that we must collectively insist that the needs of people with arthritis get a high priority. If we put our various expertise to work on solutions, the prospects for arthritis care and the ultimate cure will be substantially improved.

We in organized labor can help. For instance, we think our structure of inplant community service union counselors can be used to help get authoritative information to working people. We think that with appropriate orientation, that our union counselors can be an effective resource to people with arthritis at their place of work... especially in working situations that do not have full-time medical service.

We want the Commission to know that organized labor in Wisconsin is concerned. We stand ready to be part of the development of a coordinated network of service resources to help people with arthritis and their families in any way possible.

Thank you.

DONALDSON: Are there questions?

What is the present function of these counselors; would they be in a position to begin to supply information of health, essentially health types like this?

SCHAEFER: To the Commission?

VOICE: You were talking about the union counselors -- resources persons.

SCHAEFER: Yes; I believe that if they were properly oriented that they could convey information on arthritis treatment and other solutions to arthritic problems.

VOICE: Ms. Seelhorst here is acting in such capacity in Athens, Ohio and has telephone calls from Kentucky, is it? In other words, you don't

need a trained medical person to provide such simple sources of information.

SCHAEFER: We agree. Our union counselors have been very effective in other fields, particularly in the area of social concern. I would practically guarantee that they would be equally as effective if they had the proper orientation.

DONALDSON: Well, thank you. Certainly with the support of labor and industry, when we go back to Congress we should have the right people on our side to help us gain the appropriations that we so desperately need.

Thank you very much for coming. Now, Sam Geller.

TESTIMONY OF  
SAM GELLER  
SPOUSE OF ARTHRITIS PATIENT  
NORTH DAKOTA

GELLER: The cause for and of arthritis is very close to me. I am herein making a plea for our area that our people not be overlooked.

In October, 1974 through the North Dakota Regional Medical Program the State achieved a diagnostic evaluation community referral Arthritis Center at Fargo, North Dakota which is located on the eastern edge on the Red River. Fargo was chosen as the site for this program because it is the only city in our State which had specialists in all of the aspects of rheumatological disease.

North Dakota is a state of 70,665 square miles and approximately 618,000 people. We do not have the facilities or expertise to house a National Resource Center although we feel this is the key in finding the cause and cure for arthritis. The best approach in the Dakotas appears to be the continuation and extending of the model center now established to encompass the entire State through outreach in the areas of treatment and training. I know that the staff at the Center is willing to share their data, protocol, and procedures, and are willing to go out and assist other areas in the State in establishing a similar facility to serve the arthritic in central and western areas of our State.

Outside of the Arthritis Center in Fargo, the nearest facility of expertise in rheumatoid disease is the University of Minnesota and Mayo Clinic. These are located approximately 350 miles from the eastern edge of the Dakotas. To these there is minimal access due to few commercial means of transportation and the weather element. Overcrowded patient conditions within these existing medical facilities make for long periods of waiting to be seen. To the west, expertise in rheumatoid diseases would be Spokane, Washington, some 1200 miles distant.

The Dakotas are populated primarily by people engaged in farming activities. If any one group of people are more frequently struck by arthritis than another, it appears that farmers rank high. This in itself states a primary need. Secondly, their occupation literally prohibits

absences from their vocations (farming, ranching) even if they had the means to get to the outside existing facilities.

I cannot overly stress the geographic isolation that predominates the Dakotas. Many areas do not even have a general practitioner. The patient, the general practitioner or referring physician can seek solace in having the Arthritis Center of Fargo. However, the Regional Medical Program is to be phased out, so we are highly concerned that this Model Clinic, so absolutely a necessity, might be again lost to our people.

In summation: I have lived with my wife, Toba, a victim of severe rheumatoid arthritis for 31 years. I know the hell of no help, no relief and little understanding by others that these people must live with.

My PLEA is that in program developing you not overlook rural Dakota.

As I told you at the beginning of my presentation, my name is Sam Geller. I am 64 years of age, self employed, and have a high school education. With the exception of 38 months in the army, I have always lived in Fargo, North Dakota.

On August 20, 1944, while on furlough, I married Toba Marcovitz who is now 57 years of age. We have been married 31 years, and we are the parents of three sons who at the present time also live in Fargo, North Dakota.

For the past 29 years my wife has suffered from arthritis, which has progressively become worse. During those 29 years she has had surgery on all of her toes, surgery on all of her fingers and both wrists. The hands will require further surgery. Synovectomies on both knees were performed, followed by total replacement of both the knee joints. Within the past two months the right hip joint has been replaced; within the foreseeable future she faces further surgery on her right elbow and right shoulder. Only because the surgical processes have not been perfected is the reason why this surgery has not already been performed.

She has taken Wetherby vaccine, gold injections for 25 years, ACTH, cortisone, nandearil, Indocin, motrin, anti-malaria drugs, aristocort, Hydrocortone, Prednizone, generous doses of aspirin and acupuncture for relief of pain. She has been advised and examined by Drs. McNider, Wetherby, Minneapolis, Phillip Hench, Paul Andrenie, O'Duffy, Combs, Conn, Cooper, Paul Lipscombe, Carpenter, and Richard Bryan all of Mayo Clinic, Rochester, Minn.; Dr. Lester Wold of the Fargo Clinic; Dr. Ulmer and John L. Magness of Dakota Clinic, Fargo, N. Dak.; Dr. Robert Persillen of San Antonio, Texas.

Need I tell you of the pain wracked days and nights? Need I tell you of the sleepless nights and the mental anxiety? Need I tell you of the miles travelled seeking relief, help, solutions, or of the thousands of dollars expended for treatments, therapy, and surgery in an effort to relieve the pain?

Yet we live with hope that tomorrow a cure or a remedy for this crippling disease will be found.



But what of the hundreds of thousands who are also affected with the disease, who cannot afford to travel to Mayo Clinic, who cannot afford to have joints replaced, who are unable to seek the best medical advice for one reason or another? What hope, what relief is there in store for them?

Gentlemen, I plead for your help!

A nation which has the knowhow and the where with all to place men in outer space and a nation which can construct a seven billion dollar antimissile base, in my home state, which is already reported to be obsolete, can surely fund and support a program to help those so sorely afflicted with the crippling disease known as arthritis.

Thank you.

TESTIMONY OF  
WILFRED de St. AUBIN  
PILOT GERIATRIC ARTHRITIS PROJECT  
UNIVERSITY OF MICHIGAN MEDICAL CENTER ANN ARBOR

ST. AUBIN: We would realize the fear that they have of disability and activity limitation from arthritis. Although osteoarthritis does not necessarily threaten the quantity, it sure does threaten the quality of living. We know today that by appropriate treatment the application of treatment that we know now, much can be done to relieve the pain and the distress and maintain functional ability.

Again, I would like to echo the plea of that lady that did that so effectively; she pleaded for action now. There are millions that need some help now. Of course, we welcome the opportunity to know -- we know that there is an Arthritis Act that our National Government is concerned-- and to have an opportunity to put some input before the Commission, to ask their consideration; and we recognize the need for intensive research. No question about it. But we hope that the research will not be done at the expense of neglect of the problem of the millions of older people. You know the act specifically refers to children, but no mention is made of older people, the principal victims, or of the exorbitant financial crippling impact of arthritis; perhaps in this respect the act is deficient.

There is a vast untapped potential in the community. I can speak for our own community and area, and I think the others are the same. We want to help. We know it is a serious problem; we have found that out. Thanks for the Project, the Pilot Project that has been operating in our area. We have been able to arrange and support the help to a lot of people. Now social agencies, church groups, United Way agencies, people with whom we work, counseling; are waiting for leadership and guidance. How can we help. And I believe that that guidance and that leadership perhaps in the form of demonstration projects could and should come from the Federal Government. It does not exist in general, except where something can be done. We have asked our Mr. Alan Jette to describe an approach which we think will help fill the gap that there now exists in the health care delivery service.



I would like to say just one word: I honestly believe on the basis of the people that I have worked with, places I have been, the groups of older people that I have met, senior citizens groups and different parts of the country, that I think that they would agree with the things that I have said to you this morning.

Thanks for the opportunity to be here.

DONALDSON: Thank you, sir. We would ask Alan Jette if he would come to the table at this time because he will be our next witness. We were asking Alan Jette to come to the table. While he is coming, I would just like to take the moment to recognize the presence of the medical director of the project, Dr. Ivan Duff. He is here in the audience and, it is unusual for him to be this quiet; but your presence is felt. Would you please go ahead.

TESTIMONY OF  
ALAN M. JETTE  
PILOT GERIATRIC ARTHRIITS PRCT, UNIVERSITY OF  
MICHIGAN MEDICAL CENTER, ANN ARBOR

JETTE: I am Alan Jette, a physical therapist at the University of Michigan and a program associate with the Pilot Geriatric Arthritis Program which is one of the 29 Regional Medical supported pilot programs.

Mr. de St. Aubin has described the pressing need for arthritis care in the older population. We as professionals feel a major barrier is an appalling lack of financial support for a comprehensive range of arthritis treatment resources. Even in areas where physician and allied health professional services are available, restrictive third party coverage renders them inaccessible to many individuals, especially the elderly. In addition, there exists major client barriers to seeking care. They include: transportation difficulties, pain and functional impairment, the myth that nothing can be done, and reluctance to come to medical centers. In attempting to overcome these barriers and to fill in the gaps in existing arthritis care, our program has developed four methods. These methods specifically relate to the priorities five, six, eight, and thirteen mentioned in section III of the Arthritis Act.

We recommend the development of community outreach in conjunction with existing community agencies. Outreach, first of all, increases the visibility of arthritis resources. Secondly, it increases public awareness of arthritis needs and what can be done for them. Thirdly, outreach can reach the socially isolated, homebound individual whom is least likely to seek the care they need. Arthritis screening as used in our program permits: 1) the identification of needs, 2) the initiation of a treatment plan, and 3) referral to the least intensive, most appropriate level of care. To meet the challenge of scarce physician resources which was repeated over and over this morning, we are utilizing nurse clinicians and volunteers in these arthritis screening activities. There is a wealth of untapped resources in the allied health professions. Community based consultation or satellite clinics have been one further method of reducing

financial, geographic, and transportation barriers for clients in our program. These clinics are cosponsored by the Arthritis Foundation, and are held in community halls, churches, and schools. A full range of professional services are available, including rheumatologists, podiatrists, occupational and physical therapists, nurses, social workers, and dieticians.

If necessary, referral to the medical center is possible to meet the needs of over a quarter of our patient population who demonstrate mild comoderate symptoms of arthritis. Group education seminars are conducted by the allied health professionals. The seminars provide information about arthritis and its treatment. Compliance with established treatment programs is often a major problem for older individuals with arthritis. Long-term support groups are one method of meeting this problem.

These groups strive to develop peer support and encourage the continued compliance with treatment in addition to providing general information about arthritis. Systemic evaluation is currently being conducted for all these activities of our Project.

It is our recommendation that this Commission establish similar arthritis health care programs across the country, to assess both the cost and the effectiveness of providing early and comprehensive arthritis care. We further recommend these programs be given adequate time to develop, mature, and be evaluated. The development and use of valid and precise measurement tools is essential to accurately assess the effect of these programs. Evaluation should be a requirement for funding. Having completed the first year of our program, we can speak positively to both public and community professional encouragement and support for this type of program. We believe that properly designed and implemented demonstrations will provide the necessary data to support the hypothesis that early and optimal arthritis care can be most effective. It is our hope that this data will then be used to facilitate long overdue changes in the health care reimbursement system.

Thank you.

DONALDSON: Thank you, sir. We will now entertain questions for either Mr. St. Aubin or Mr. Jette.

SHIELDS: You alluded to the fact that there is a great wealth of allied health professionals out there that can assist in this area. Your comments regarding whether or not they are well enough trained at the moment to handle that -- or do we in fact have physical therapists who are still putting hot packs on people and addicting them to our departments or are they trained to handle a chronic disease?

JETTE: No; when you mentioned your comment previously, I could not agree more that there is a great need to get physical therapists and other allied health professionals out of the medical centers, to stop giving the hot packs and making patients more dependent, and teaching them how to effectively manage their disease.

SHIELDS: So you don't feel that they are adequately trained at the present time in their basic training program, and that it will require additional training to get them skilled at chronic disease management?

JETTE: That is right.

BATCHELOR: I am interested to hear you describe a program here that has been in operation for a year. Your teachers that you described have been considered by the group consultants advising the Commission on setting up community programs. I just want to register our interest. Do you have any progress reports on any program that is one year young? We would certainly be glad to have them.

JETTE: I have our annual report, which I can make available.

VOICE: You mentioned public support has been achieved, and I wondered in terms of actual monetary support, since the RMP programs had hoped that there would be a gradual evolution into self-sustaining funding, have you seen some of this appear?

JETTE: No; I was speaking specifically to public and professional support of the activity, not financial support.

VOICE: Has there been any attempt, though, to evolve transition into ultimate support by the region itself?

JETTE: I am not sure of the specifics, and I am not qualified to address that; but Dr. Duff, I am sure, would.

VOICE: I just had one comment that I would like to make. I guess it is probably directed more to Sam Geller, because he brought it up. I recognize that since being on this Commission, I have began to look at patients differently. I used to think that when I would hear the term of 20 million people out there who were suffering that needed help, and now I find myself saying there are 20 million potential voters out there. I would hope that you would all recognize how important that really is. If we could somehow mobilize together and not only do we have 20 million voters, but we have a husband, a wife and family members. Maybe that is 50 or 60 million people who are potentially able to tell Congress to do something about arthritis. Maybe we could then get money funded for arthritis care instead of -- like putting a man on the moon -- we could also have a much greater impact on arthritis, but I think you make the difference.

ST. AUBIN: I think they are there, and I think they can be if we help them get the information.

VOICE: They not only are voters, but they pay taxes, too.

VOICE: That is right; but being voters, that is what impresses Congress because they got there by votes.



DONALDSON: I am afraid we must go on now and I would ask Dr. Liang, Richard Edwards, and Claudia Standorf to come forward. Dr. Liang, we are glad you could be here with us.

TESTIMONY OF  
GEORGE C. LIANG, M.D.  
RHEUMATOLOGIST, GUNDERSON CLINIC

LIANG: Mr. Chairman and Committee members: Thank you for this opportunity to testify here. My name is George C. Liang, and I am one of the two rheumatologists at the Gundersen Clinic of La Crosse, Wisconsin.

The staff of Gundersen Clinic Lutheran Hospital, La Crosse is actively involved in the care of arthritis patients, education of house officers in rheumatic diseases, and plays a major role as a consultative service for the surrounding tri-state practicing physicians within an approximately 60 mile radius. I think we have a growing patient population; between 200 thousand and 300 thousand population.

The clinic emphasizes quality care for the patient, physician and patient education, and research. Our priorities are in that order; the patient care first, and then their education, and then research third. Now we have more than a hundred specialized physicians at this medical center, including a physiatrist, two podiatrists, and four or five orthopedic surgeons. We are adequately supported from the allied health professions; occupational therapists, physical therapists, social worker and nurse. We have a sophisticated hospital laboratory to do all the tests needed in the care of arthritis patients. We also have an excellent educational programs for interns, residents, and medical students from the tri-state area.

As several speakers alluded to earlier, the modern quality care of arthritis patient requires a cooperative multidiscipline team effort. At this medical center we have the capability to render arthritis patients such service. However, the patient is hindered by limited financial resources. Most patients in our area cannot afford to pay the expenses involving various, multidisciplined professionals and the sophisticated laboratory costs, especially on an outpatient basis. The inpatient basis that we use has some kind of cover, but particularly not on outpatient basis. So, our diagnostic, therapeutic, and rehabilitative capability for the patient is therefore not fully appreciated and utilized. I will give you an example: Our occupational therapists put together a patient education program -- self help patient education program. She tried to put together all the different disciplines to offer patients some kind of education program. But the problem we are facing is the cost of those educational programs. As we all know it seems to be that our hospitals are to get some funds to offer a patient a free service for dietary or diabetes education programs, but there are no resources available in the education program for arthritic patients. Now, the laboratory of this hospital is doing us some applied research activities related to the field of arthritis and rheumatism through a grant from the Arthritis Foundation of Wisconsin. But the fund is not adequate to support the research effort. The detection and management of various arthritic patients requires

development on newly established laboratory techniques. There is a great need for additional funds to expand laboratory facilities and personnel to develop various new techniques.

So just in brief, Gundersen Clinic Lutheran Hospital complex of La Crosse can easily become an arthritis treatment center for this tri-state area, including the western part of Wisconsin if additional funds are available. This is the best available local resource to improve and render services to persons with arthritis in this area. Thank you.

DONALDSON: Thank you. Could you give us some estimate as to what the population is in the geographic area that you would serve?

LIANG: I think we serve somewhere between 200 thousand and 300 thousand population.

DONALDSON: And what kind of additional facilities and support would you need to become an effective arthritis center, as you described?

LIANG: I think we would need resources in some coordinative effort or some kind of administrative effort to put all these resources available to the patient. Then we would need some specializing nurse, or somebody who would be interested in putting all this coordination together. I have been trying hard myself to do all this business together. It is difficult with being busy taking care of patients; it is difficult to put all this administrative effort together. Also, we would need resources for some clinic research, which I am interested in doing. I spend about 10 to 15 percent of my time doing the laboratory work and some applied clinical research. I have difficulty getting the appropriate funds to do this kind of research. I spend 85 to 90 percent of my time doing patient care or education of the physicians. It is difficult to split between how much time I spend doing education, because we have 33 interns, residents and medical students together, and they could ask me anytime, any question they have about rheumatic diseases.

LEWIS: Doctor, how do you spell your name; and are you a rheumatologist?

LIANG: I am a rheumatologist, my name is George C. L-i-a-n-g.

DONALDSON: If there are no further questions, thank you very much.

LIANG: Thank you.

DONALDSON: We will now proceed with Richard Edwards.

TESTIMONY OF  
RICHARD C. EDWARDS  
DIRECTOR OF SOCIAL SERVICES  
METHODIST HOSPITAL

EDWARDS: I want to briefly underscore two observations about the nature and consequences of arthritis, and in so doing, suggest priorities for the stewardship of money under the National Arthritis Act. I speak both as a professional social worker and the 33 year old son of a woman crippled for my lifetime with rheumatoid arthritis.

First, about the nature of the disease.

Arthritis is one disease entity which must continually combat an evil greater than itself; namely, public ignorance.

How many times have frustrated health professionals said to one another, "If people only knew..."

Arthritis is not an "old person's malady", not "something you must learn to live with." Arthritis is everyone's disease. We know that.

Copper bracelets don't help. We know that.

Charlatans, quacks and profiteers proliferate and capitalize on public ignorance. We know that.

Too often, well intended but misinformed general practitioners give poor counsel and care to persons afflicted with the various types of arthritis. We know that.

The list goes on --- Misinformation producing misunderstanding resulting in mismanagement or, worse, no management.

The National Arthritis Act simply must let the people know what we know.

The public must be better educated in the disease of arthritis, to understand the care and treatment of persons afflicted, to know where to go for good care, to know when they are receiving good management of their disease, to gauge their expectations of the health care delivery system and their expectations of persons with arthritis.

To date, we are remiss for our failure to inform.

We must fund a campaign sufficient to raise the consciousness of the American people relative to the disease of arthritis; challenge the creative genius of media experts to reach the people with information that separates fact from fiction; and, go beyond the traditional 30 second celebrity spot-commercial at fund raising time.

I believe if we take seriously the need to educate the public and raise the level of awareness, we will have a lesser difficulty creating



funds for basic research, the training of rheumatologists and allied health professionals and, ultimately, be of better service to lives of persons affected by the disease.

Secondly, an observation about the human consequences of arthritis.

People are made of feelings, social roles, relationships and resources in addition to bones, tissues and organs.

My mother's disease was diagnosed and managed in our home town at one of the world's most famous medical centers. At no time in my growing up years did anyone reach out and be sensitive to what it was like for me having a mother crippled and deformed with arthritis. No one ever explained to me the nature of the disease. No one cared or inquired about my feelings, how I was coping or what the disease meant in my life. This was a gross, painful, and unnecessary neglect of the human element, something which we must not tolerate.

The patient treated for arthritis is a person from a unique social context, a person with feelings, someone's child, someone's spouse, someone's parent, someone's employee, someone's friend. Arthritis is not a private disease. The human element is sizeable and must be assigned a high priority.

The very nature of chronic disease demands a reordering of life styles, social roles, relationships, and resources to accomodate the reality of the disease. Psychosocial, sexual, and economic consequences can be profound and far-reaching, potentially as crippling as the disease.

The social worker brings to the health team basic knowledge and skill keyed to the human consequences and critical to the comprehensive management of the disease and lives it effects.

The social worker can provide direct services to the patient and his family, being supportive, providing information and resources as they struggle to cope with the realities of the disease.

The social worker can counsel with members of the nuclear and extended family to educate and interpret for them the nature and consequences of the disease and its impact on their lives.

The psychosocial knowledge, skill, and sensitivities represented by the social worker must also be incorporated into the education and training of allied health professionals to further insure service to the total human element. Another role of the social worker in service to the person with arthritis is that of advocate. The social worker can work within the community and the health care delivery system to insure the patient's right to accessible, quality care, identify the deficiencies in the system, and mobilize resources towards system change.

The role of the social worker becomes increasingly apparent. Patients with arthritis are people made of feelings, they represent social roles and relationships. They must function in a unique social context and cope as best they can with the reality of their disease. The people around

them need the support, reassurance, education, and assistance that is best provided by a skilled social work practitioner.

In summary, I would encourage those of you charged with the responsibility of recommending funding priorities for the National Arthritis Act to include money sufficient to properly educate the American public and to provide qualified personnel sensitive to the psychosocial needs of persons afflicted by the disease arthritis.

DONALDSON: Thank you. Are there questions?

VOICE: I want to thank you for your testimony. I think it reminds us of something we tend to forget sometime; that we can pay attention to hours lost, and taxes lost, but the human cost of suffering is hard to measure, but just as real.

EDWARDS: Thank you.

DONALDSON: Claudia Standorf.

TESTIMONY OF  
CLAUDIA STANDORF  
MILWAUKEE DIETETIC ASSOCIATION

STANDORF: I am Claudia Standorf, R.D., Dietitian II, Milwaukee County Institutions, Milwaukee County Medical Complex. I am writing-speaking on behalf of the Milwaukee Dietetic Association.

In the development of a National Arthritis Plan, we would like to see included a strong coordinated approach to nutrition research in relation to arthritis and related musculoskeletal diseases. We would also like to see, as part of the continuing care for patients with these involvements, a vigorous communication of the information derived from this coordinated effort. This communication would be inclusive of both the medical and lay communities.

How often has the statement been made that all is necessary is to "Maintain Good Nutrition." This does not answer the complexity of questions such as: What effect are the chemo therapeutic agents having on the nutrients that the individual has ingested? Are Dietary modifications necessary for the primary disease? Does the physician have enough knowledge of nutrition and the nutritional needs of his patient to care for his patient without the aid of the dietitian or nutritionist?

Since nutrition is a relatively new science, how absolute can we be about folk medicine cures for arthritis and related musculoskeletal diseases unless research is conducted to obtain the data necessary with regard to nutritional needs and the effects of nutritional modifications in the treatment of these patients?

We realize that there are many disciplines that have special interests in the care of patients with arthritis and musculoskeletal diseases, and

that there will be many demands for the monies available to the National Arthritis Plan. However, we recommend strong consideration to a program that includes a nutrition care plan that is inclusive of gathering pertinent data in research projects, of disseminating the information from such research projects to the medical and lay communities, and in counseling physicians and other members of the health care team and of the patient, his family and members of the community.

Recommendations for funding this type of program are withheld until more is known about the structure of the National Arthritis Plan, but possibilities could include grants to research projects and/or specific individuals conducting such research or involved in educational and/or counseling positions.

I thank you, the members of the National Commission on Arthritis and Related Musculoskeletal Diseases, for giving us this opportunity to present this statement.

DONALDSON: Thank you for coming. Are there questions? Yes, please.

VOICE: Would it be fair to state that because of no one particular fault there, the field of nutrition has not had a lot of scientific studies devoted to it, outside of some of the necessary work done during the war when the care and feeding of soldiers was important?

STANDORF: Well, there is a great deal of information now being gathered in the field of nutrition. It is a matter of what field you are interested in. From my personal knowledge, there is very little available in the field of arthritis and musculoskeletal diseases. However, there is a great deal now being gathered for cardiovascular patients. Nephrology patients are now coming in to great attention and focus, but very little has been brought in to the arthritic patient. Controversy such as developing diet for the gouty arthritic patient -- one field says that medication, unless it is not easily received by the patient -- there is no need for a diet; another says diet plus medication. There is really no basis of study that I can call that informs us.

DONALDSON: If no other questions, thank you very much, I would ask Mary Ann Lorentz, Janet Lemke, and Dr. Sundstrom. Miss Lorentz.

TESTIMONY OF  
MARY ANN LORENTZ  
PARENTS OF CHILDREN WITH RHEUMATIC DISEASES

LORENTZ: My name is Mary Ann Lorentz, and I am speaking for our parents group, Parents of Children With Rheumatic Diseases. I have a daughter, Ann, age twelve who has juvenile rheumatoid arthritis. Also in the audience are four other parents whose daughters have juvenile rheumatoid arthritis: Mrs. Matheson, daughter Diana age eight; Mrs. Martini, daughter Michel age 14; Mrs. Bearman, daughter Karen age 15; Mrs. Olashan, daughter Lisa age 10. We number 60 some families in this area.



Our group came together about five years ago. It grew out of a need to share our problems and concerns with one another. It grew out of a need to know and to attempt to understand what was happening to our children, to ourselves and to our family life. It grew out of a need to try and grasp implications of caring for a chronically ill child on a day to day basis. Such needs are not met by traditional medical care. We feel helpless as we watch our children slowly lose mobility. We feel frustrated as medical treatment fails. This child feels pain and loses hope, and both parent and child feel guilty.

Some help may be possible if physicians can be better informed about childhood rheumatic diseases so that an early and accurate diagnosis may be made. If some physicians can recognize their limitations and ask for another opinion, if some physicians can admit it when their diagnosis is incorrect or that their recommended treatment isn't adequate; if services of other health care professionals are made more available to us. Under the present system, if the inadequate treatment persists, the parent solicits another opinion; but from whom? Relatives, friends, neighbors, going from doctor to doctor and finally a quack hears. The lost time in searching for the proper medical care that is our profound right in the first place may never be recovered. It may result in physical and emotional damage to the child which may never be corrected.

The needs that our Parents Group would like this Commission to advocate are: to implement courses on rheumatic diseases, including those which affect children; to provide opportunities for continuing education in the field of rheumatic diseases. We need the establishment of parent groups in conjunction with the arthritis centers. This would provide a service. By education and information, parents and their children may thus accept a greater responsibility in the management of their health care through better understanding. Physicians are limited in their time and expertise in helping to deal with the varied problems occurring with the child who has a chronic disease. We need updated and more information or literature. As far as we know, for the parents there are only two pamphlets which are: Arthritis in Children and What Parents Need to Know About Juvenile Rheumatoid Arthritis. These are woefully inadequate. Parents seek more information to help them comprehend this disease. Information is needed to provide school personnel to make them aware of this disease. There is no pamphlet to help the child understand his disease.

Next is the financial drain and difficulty in obtaining life and health insurance. These are a constant source of worry for the parents now and for the child in the future. A more immediate financial need is for the child who is not hospitalized and who is receiving outpatient medical care and may lack accessibility to the skills of the other professionals. This is due to the cost and unwillingness of third-party payers to pick up these bills.

Schooling for the child is difficult. It is hard for school personnel to understand the disease and the adjustments needed in the child's school schedule. It is important that the child is not made to feel isolated from his peers and his regular activities. Of all the 60 children represented here, only 1 is in a special school.

We know that most of these needs require funding. We believe that it is your charge to let Congress and the public know of the inadequate funds which are available. As I hear now, there are not any funds. Other diseases receive great sums of money for education, information and research; arthritis a pittance. We believe that your charge is to make Congress open their ears that they may hear the people, especially the people and the children who are experiencing hourly the pain and frustration of rheumatoid arthritis and other rheumatic diseases. In this Commission lies the best hope of the parents and their children that continued education of physicians, nurses, allied health professionals, parents and public take place; that accurate information be given; that the need for updated and new materials be implemented; and that finally, through a concentrated effort, a cure for this insidious disease be found.

Thank you very much.

DONALDSON: Thank you. Could you tell us a little bit about your parents group; how long it has been organized and what it exactly does other than getting together?

LORENTZ: It came into existence about 1971. It was at Columbia Hospital here in Milwaukee, where about four sets of parents came together for a multidiscipline care for their child. We just sat down and got together and started talking about different things. From that we decided that, gee, there is somebody else here who is sharing the same problem that I am. It is very good emotionally for the parents; physically and educationally, it has just been very good for us. We have expanded from that original 8 couples to -- well, we have approximately 60 families in this area.

VOICE: You all met in a waiting room?

LORENTZ: Right; waiting for our children to be. And from the initial meeting, it just grew. Telephone calls were made and we finally got together.

BACHELOR: May I just take this opportunity to speak to a concern that has been expressed repeatedly here. The Act that we have today is the authority opening and not an appropriation. I think it will come as no surprise to the group here that Congress would like to see the Commission report before we get to work on the funding. The fact remains that the continued interest of people like yourselves is very important to follow through.

VOICE: Let me add even further, if I may, Dr. Batchelor. As I recall, in listening to the Deputy Director of the National Institutes of Health talking about whether there were funds or not it should be clear that the administration, particularly in the department of Health, Education and Welfare, was aware of the Arthritis Plan as of a year ago. And while there are no specific funds which are earmarked, labeled for arthritis research and demonstration, it is very clear that there were in the budget processes, several million additional dollars added to the Institute of Arthritis, Metabolism, and Digestive Diseases' operating budget as of this July when the present fiscal year started. So, although you may not see

it as a line item with a label on it, there are funds to help the Arthritis Institute carry ahead the programs that are already involved in.

MELICH: I am particularly interested in what you said about your 60 families getting...I am sure you have been a great help to each other. But my question is, how much effect have you had on those patients and allied health people?

LORENTZ: We are still trying. That is right; we really don't know. We hope to send out a mailing to the local physicians shortly. We hope to send out a mailing in the near future to the local physicians and let them know about the group. But as far as being, how should I say, out in the field and really working, no; it is just a general support group right now for (inaudible). We get education information because we do have allied health personnel come in and talk to us, demonstrations, the dialogue with rheumatologists, psychiatrists; so we are trying, attempting to educate ourselves through the help of the professions in dealing with this disease.

MELICH: Don't underestimate your ability to influence doctors, because we are finding in many areas that the patient insists on some kind of training for their own doctors and the doctors are coming to the clinics not only to bring their patients, but for on the job training, which we find is very good.

LORENTZ: That is what we hope to continually prod and question. Thank you.

LEWIS: Have you thought about developing a little pamphlet for children?

LORENTZ: Pardon me?

LEWIS: Has your group thought about taking on a little project yourself, in developing a pamphlet for children who are arthritic?

LORENTZ: I know of a couple of individuals who are trying to attempt this; yes.

MCNALDSON: Well, thank you very much.

At this point, I would like to recognize another famous rheumatologist who is in the audience. Again, she is unusually quiet, but her presence is felt and we are most pleased to have Dr. Hess here; Dr. Evelyn Hess who directs the University of Cincinnati program. And she represents southwestern Ohio most appropriately. Thank you for being here. Now we can go ahead with you, Miss Lemke.



TESTIMONY OF  
JANET LEMKE  
UNIVERSITY STUDENT; PATIENT

LEMKE: I would like to introduce myself. I am Janet Lemke. I have systemic lupus erythematosus --- a disease most people don't recognize as a form of arthritis. I was diagnosed in 1970. At that time, the doctor told me it affects more women than men, and that there was no cure for it. They told my parents that I was going to be bedridden most of the time --- these facts did not particularly help me.

Even with early and accurate diagnosis and good treatment, I didn't get what I really needed, and that was to know how to live with it.

At the present time, I am a full-time student majoring in social work. I receive financial assistance from the Division of Vocational Rehabilitation, which covers my tuition and books and gives me \$15.00 a week to meet my expenses. However, it is necessary for me to work part time to supplement my income to help cover my medical costs. I hate to ask my family for help because you see, my mother has lupus, also.

I would call your attention to what I consider a major need --- that need is realistic financial assistance. For instance, my current medical expenses consist of laboratory work of \$77.00 bimonthly, and this does not include medications or routine visits to the physician. In fact, I cannot get individual health care coverage. I can only get insurance through a group plan. Currently my group policy covers \$200.00 for outpatient work. This illustrates the unrealistic medical insurance coverage available. If I were hospitalized for the same services my coverage would be much better, but the cost to the public would also be much higher. Unfortunately, many of us do not meet the requirements for medical assistance primarily because of age restrictions or inability to prove total and permanent disability. In short, I not only have a chronic disease, but also a chronic financial problem.

I request the Arthritis Commission recommend efforts be expended in evaluating the adequacy of the present system of financial relief, as well as investigating new ways of reducing the cost of chronic diseases.

I also request this Commission not forget the less wellknown of the rheumatic diseases, such as systemic lupus erythematosus.

DONALDSON: Thank you very much. Are there questions? I really appreciate your taking a day off and coming here and reminding us of your particular problem.

LEMKE: Thank you.

DONALDSON: Dr. Sundstrom

TESTIMONY OF  
WALTER R. SUNDSTROM, M.D.  
CHAIRMAN, MEDICAL AND SCIENTIFIC COMMITTEE  
WISCONSIN - A.F.

SUNDSTROM: The primary needs for arthritis care in the State of Wisconsin, from the standpoint of a clinical rheumatologist, are:

- (1) Lack of rheumatologists.
- (2) The lack of continuing education programs for practicing physicians in primary care (pediatricians, internists, orthopedists, physiatrists, family practitioners.)
- (3) Inadequate delivery of health care to rheumatic disease patients in the outlying districts of the State of Wisconsin.
- (4) Dissemination of information to arthritic patients by the Wisconsin Arthritis Foundation.

What can be done to meet these needs?

Answer.

- (1) Lack of rheumatologists.
  - a. We need to increase the number of rheumatology fellowships at both medical schools.
  - b. In order to increase the number of rheumatologists in the State of Wisconsin, this is absolutely necessary.
  - c. Government funding to help support rheumatology fellowships in their training programs is absolutely necessary. As far as I am concerned, this is the prime need in the State of Wisconsin at the present time. To do all of the other things that I will mention will simply increase the need for physicians trained in the specialty of rheumatology. The physicians already trained in rheumatology are overburdened. We, therefore, need a new supply of physicians to handle the health care needs of patients with these diseases in the State of Wisconsin. Your support in these areas would be most welcome. Additional avenues for improvement would be in developing paramedical personnel and training programs to help in screening patients for the rheumatic diseases.

Q. Lack of continuing education for primary care physicians.

- A. The medical schools together with the Wisconsin Arthritis Foundation must increase postgraduate medical programs for physicians delivering health care throughout the State. These programs should be directed towards the pathophysiology, diagnosis, treatment, and clinical outcome of patients with rheumatic diseases. At the present time, the

Medical College of Wisconsin, under the auspices of Dr. Daniel McCarty, has started the first postgraduate program. The University of Wisconsin, Madison, at this point has not done this. A program of Federal funding and to fund new and innovative ideas for educational instruction for physicians throughout the State is needed.

- Q. Inadequate delivery of health care in the outlying districts of the State of Wisconsin.
- A. By definition, there are approximately 13 active rheumatologists in the State of Wisconsin. There are two at Marshfield, one at La Crosse, one at Monroe, three in Madison and five in Milwaukee. One rheumatologist in Madison is about to leave for an academic appointment in one of the Far Western States. As a direct result of the renewed interest in the rheumatic diseases, young house staff officers and medical students are now being more adequately trained in rheumatology. However, there is a large congregation of physicians who have never received any adequate training in the rheumatic diseases. They, therefore, have a very negative approach to patients with rheumatic diseases. The patients are suffering as a result of this. The patients are receiving inadequate workups, incorrect diagnoses, and improper therapy. As a result, their outcome is poor. Because of an improper number of trained physicians in the State of Wisconsin, and because of a reduced supply of primary care physicians in the outlying area, many patients with arthritis are not even seeing physicians. One suggestion I would have is that we have Wet Clinics going out into these communities, seeing patients and helping to instruct primary care physicians in the proper management of arthritis. This could be supported by Federal grants.
- Q. Dissemination of information to patients with arthritic diseases.
- A. This, primarily, is the responsibility of the Wisconsin Arthritis Foundation. Because of limitation of funds in the Wisconsin Arthritis Foundations, we are strapped in trying to develop new programs for the dissemination of care to patients suffering from the rheumatic diseases. Part of the practice of medicine is disseminating information to patients with diseases, and to patients who feel they have a disease. This can be done by new and innovative programs. Funding is needed to assist the Wisconsin Arthritis Foundation in developing informational and retrievable data systems. In order to define the number and/or population of patients with rheumatic diseases in the State of Wisconsin and to develop new means of delivery of information to these patients about their rheumatic disease. These funds do not now exist.

To Summarize:

- (1) The unmet needs are primarily the lack of specialists in rheumatology to deliver health care and to help educate primary care providers.
- (2) Lack of facilities, resources, to educate primary care providers.



- (3) The lack of adequate health care delivery systems to the rural areas of Wisconsin.
- (4) The lack of funds to properly identify and distribute information to rheumatic disease patients in the State of Wisconsin.

DONALDSON: Thank you. Are there questions?

BATCHELOR: I would like to ask Dr. Sundstrom, in a decade or more of working in this area of specialists, what do you see as the promising (inaudible) in your actual experience in helping the primary care physician look after the patients? What I mean here is obviously the question, to what extent will the care of these patients be a responsibility to the primary care physician. As most of the specialists, what do you gain from your experience here in procedure and development?

SUNDSTROM: I think the primary care physician has a great role to play. I think he needs assistance from people trained in rheumatology in order to define the problem --- to outline the management program. He certainly is with the patient more frequently and on a day-to-day basis as far as management is concerned. I think that we need to go out into the community and see the patient and physician together. That is an immediate problem that I think we have in the State of Wisconsin.

A year ago, through the medical and scientific committee, WRMP, and in the Arthritis Foundation, we had three outreach programs in the State that went into the northern districts of the State with referral teams and did just this; and they were well received. We hopefully have on the docket for 1976 a more aggressive and total program. That, to me, reaches an immediate need for the care of patient and physician in the State of Wisconsin. The long-term need, the long-range planning need is developing rheumatologists. It is not to say if you develop 10 rheumatologists in the State of Wisconsin, how many will stay here, but at least they will go somewhere and deliver care and rheumatology.

DONALDSON: One of the suggestions we heard earlier was that it would be appropriate to develop a six or eight week courses for family practitioners. The question raised then was whether or not this was -- while it would be nice -- was it a practical solution to getting...

SUNDSTROM: I personally don't think that is a practical solution. I think it is a theoretical solution. I would think it would be better to bring a man one day a week to the training center, or possibly have someone go out there. There are many reasons why in a sterile atmosphere a man may not learn as much as he can learn about a disease. I think he needs the practical application. And economically speaking, family and social pressures to get cut of his community and come for six to eight weeks without replacement in an outlying district would be most difficult, I think.

VOICE: I come back to your first point, because as I look at this map of Wisconsin I see a very large uncovered or apparently uncovered part of the State. I question the ability, even with good intentions of your

existing strengths and clinics to get into that region without further recruitment of more rheumatologists.

SUNDSTROM: We need more rheumatologists to serve that area of the State that you are pointing to; there is no question about it. The manpower committment would be impossible.

DONALDSON: Well, thank you very much. I am afraid our time constraints are such that we always have to move when we would like to ask more for more information. We call now on Dr. Frank Schmid, Victoria Graziano, and Richard Jacobson. Dr. Schmid.

TESTIMONY OF  
FRANK R. SCHMID, M.D.  
PROFESSOR OF MEDICINE AND CHIEF, ARTHRITIS AND CONNECTIVE TISSUE  
DISEASES SECTION, NORTHWESTERN UNIVERSITY;  
MEMBER, SCIENTIFIC, MEDICAL AND SCIENTIFIC ADVISORY COMMITTEE  
ILLINOIS CHAPTER, ARTHRITIS FOUNDATION

SCHMID: Mr. Chairman: I am Dr. Frank R. Schmid, Professor of Medicine and Chief of the Section of Arthritis and Connective Tissue Diseases at Northwestern University and Medical School in Chicago and a member of the Scientific, Medical and Scientific Advisory Committee of the Illinois Chapter of the Arthritis Foundation. I speak today on behalf of the great need in our region of care for patients and training for professionals. I speak to you not only to tell you we desperately need support, but also to tell you that we have not been idle and have been using current resources to their full limit.

In Illinois we face the following challenge: Rheumatological care for a population of over 12 million people is needed, with a major area of concentration of about six million people in the northeastern corner of the State, namely the metropolitan Chicago area. The Gary industrial area of Indiana is contiguous of the Chicago area. In the entire State, and in the Gary region, there are but 20 rheumatologists; 17 in the Chicago region and the remaining three in Urbana and Rockford, both about 100 miles from Chicago. Westward beyond Rockford, for about another 100 miles and southward beyond Urbana, for over 200 miles, no rheumatological center exists in a region with but a handful of smaller cities in a largely rural area. Referral care for people in the southern Illinois region gravitates to St. Louis and for other areas to Rockford, Urbana, and then Chicago. In the metropolitan Chicago region some neighborhoods are devoid of adequate medical care as well as rheumatological care. Ghetto areas exist for blacks, about 50 percent of the cities' population; for appalachian whites; and for spanish-speaking population, mostly mexican. Here referrals occur sometimes late, sometimes never to the cities' medical centers and clinics. Only 8 of the 11 clinics identified as arthritis clinics have a rheumatologist. The demand for care obviously is great, greater than can be adequately met by these units. For example, at Northwestern University clinic we have a waiting period of over four months for non-emergent but painful arthritic patients, despite over 2500 patient visits per year. An adequate staff to correct the situation is lacking. Only three centers in the region have an active training program



for rheumatologists; Northwestern, the University of Chicago, and Loyola. Their annual output of physicians with training in rheumatology averages about five per year, and of these some are research oriented and others are attracted to other regions of the country. Until this year, the States' largest medical school, the University of Illinois, had no full-time rheumatologist; and three of the other seven medical schools, including a school of osteopathy, have no full-time rheumatologist. Thus, the key professional of the arthritis care team is not being produced in adequate numbers. The scope of the problem is detailed on attached materials that I am submitting.

Every arthritis center in the greater Chicago area last year committed itself in writing to tackle the problem in a unified fashion. As a consequence, a single structure, the Midwest Regional Arthritis Center, has been created as a channel for administration and funding. Without outside support, each active medical school has undertaken specific assignments usually within and extending from its geographical location in the city, thus again using Northwestern University as an example. We have pledged our efforts to develop arthritis units at four hospitals affiliated with our parent university in the north and northwest greater Chicago area. Another instance of this collaboration is the creation of a nurse-practitioner program in arthritis. Two nurses have already been trained in the last year under the aegis of the center, and six additional nurses are being recruited for our next class. Instruction is provided for this class by all the active medical centers in the arthritis unit. We believe that this type of interaction may be one of the few, if not the only instance of a large urban area of the country in which all existing university units have interacted in this fashion.

Our area has undertaken leadership in approaching the question of the impact of arthritis upon the worker and industry. Two regional conferences involving major corporations and their medical and personnel departments have been held; one in 1973 and one in 1975. A national conference is being planned, to be headed by Dr. Peter Wolkonsky of our region, that will again address this issue. What about the future? Facilities and faculty are working on basic problems in rheumatology. Medical institutions including the rehabilitation center, a regional resource with over 100 inpatient beds, and other hospitals are available. A woefully outnumbered group of rheumatologists and other health care professionals have tried and continued their efforts to extend care and training.

What is desperately needed is support for such programs that now only begin to approach the full problem. Our total budget in the current year is just over 200 thousand dollars for all training, research, administration, and patient care. We hope to double this without outside funds. We can address questions of cause of arthritis. We have workers funded in virus studies, studies in altered cell membrane structures and rheumatoid arthritis, immune complex and complement-mediated reactions, curing alterations and gout, genetic factors involved with the HLA system. We can address training needs, although unless funded more adequately, we will not catch up, not to speak of keeping up with the problem. And finally, we can address patient care needs if we can secure additional funding.



Thank you.

DONALDSON: Thank you very much. Will you have some written material on this Midwest Arthritis...

SCHMID: Yes, sir. I didn't detail that, but in the documentation that will be available is a structure we have created; its officers, the projects that have been planned, those that have been initiated.

VOICE: And this is composed of institutions in the Chicago area or is it further area wise?

SCHMID: The major medical strength is in the Chicago area, but it encompasses the northern half of Illinois and takes in the Gary region of Indiana, which has no...

VOICE: What is wrong with the southern half of Wisconsin?

SCHMID: The southern half of Wisconsin --- I may have other spokesman. I wouldn't want to speak for that.

DONALDSON: I think we had better move along. Victoria Graziano.

TESTIMONY OF  
VICTORIA GRAZIANO  
DIRECTOR OF PHYSICAL THERAPY  
ST. MARY'S HOSPITAL

GRAZIANO: Services to arthritis victims cannot be increased and improved until they are first established. To establish services, the needs of arthritis victims must be identified. This cannot be accomplished until the public, physician, allied health professional, and patient are educated or informed of the basic management of arthritis.

Progress in education cannot be made presently under the misconception of "a crippling disease of old people."

The patient seen by a physical therapist needs to know about their disease. They need to know about medication, exercises, and specialists trained and available to assist them with their chronic disease. The knowledge is motivation, and a patient needs motivation to reach the highest level of independent function which is the goal of physical therapy treatment.

Funds need to be generated to bring the present expertise in the field to others through research, investigation, technology, and mobile health teams. The number of victims far outweighs the number of trained health professionals in the arthritis field. The scale must be equalized for assistance to be available. Once basic management is available, then more sophisticated areas of care can be established.

Financially, publicly, personally, and medically, arthritis must be attacked through knowledge. This can be attained through funded educational programs on all levels.

"The needs are many; the dollars few."

DONALDSON: Thank you. Are there questions? Out of consideration to your voice I am sure there are no questions, but we do appreciate your coming even you don't feel up to par.

At this point I would like to recognize the presence in the audience of Mark Mueller, who is head of rheumatology at the University of Wisconsin. One of the reasons I have done this, this morning, is to emphasis to all of you what broad support there is among the field of rheumatology for the actions of this Commission. How involved they are; these are all very busy people who have come, some of them a considerable distance, because of their very sincere interest in the functions of the Commission.

Now, if we could hear from Richard Jacobson.

TESTIMONY OF  
RICHARD H. JACOBSON  
PRESIDENT, WISCONSIN ARTHRITIS FOUNDATION

JACOBSON: My name is Richard H. Jacobson. I am vice-president for administrative services at Blue Cross of Wisconsin. I am also president of the Wisconsin Arthritis Foundation. In this latter capacity I am here to represent the hopes and needs of over 400,000 men, women, and children in Wisconsin who have arthritis or other forms of rheumatic diseases.

On their behalf, I would like to say thanks to you members of the Commission for accepting and vigorously pursuing your important assignment.

Now, I would like to underscore where I think the Arthritis Foundation fits into the plan for doing more for people with arthritis.

I have, for the records of the Commission, over 200 letters of testimony from people who have arthritis and from people who serve their health care needs.

The consensus of their concerns and their recommendations reflect in large measure what we have already heard this morning. Our constituency says their most urgent, unmet needs are: to have better care, to see more research being done; they want increased training of doctors and allied health personnel in the rheumatic disease field; they want intensified and expanded public awareness designed to put more pressure on doctors to practice a better brand of arthritis care; they want more patient education so that people with arthritis might know their disease better and what they should expect from effective medical care.

The underlying thrust in all the letters is that we want an improved and increased treatment capability. We want a cure. And, we want these things to happen a lot faster than they are.

The Wisconsin Arthritis Foundation sees its role as that of advocate, as the mobilizer of public concern, and as a supporter of innovative approaches to better services.

We appreciate the public prominence which the Commission has generated for the cause of arthritics. We stand ready to help in any way possible to bring success to the Commission's efforts.

Thank you.

DONALDSON: Thank you, sir.

VOICE: I am particularly interested in the fact you are here to ask. If I hear correctly you take part in the Blue Cross. Perhaps you could help us, I think in between your deliverance we have heard here, and we have heard at other hearings, the expression -- the concern about more medical coverage. We think of the care -- patients with rheumatic disease is largely an outpatient activity, my main area of interest here is developments of my head towards the getting care and support located (inaudible).

JACOBSON: Yes; I did hear comments today, and I am very much aware of this particular problem. I am not an actuary, but what it really boils down to is an actuarial type problem. The insurance industry per se, I think, is able and willing to provide the type of care that is needed. The problem is the funding that is necessary. And by and large, it becomes a matter of how much an employer or how much a consumer is able to pay; and that is the nub of the problem. There are programs that are being expanded by the industry as such, moving more and more towards care outside of the inpatient level, outpatient particularly, home care, other types of care and extended facilities, but all of these things have a significant cost factor. And I think the insurance industry, as well as the consumer, needs help in order to provide this kind of care.

VOICE: Well, certainly if such costs could be spread over a sufficiently broad population, that the particular individual that is unfortunate enough to be stricken with a disease like this would get help from the large pool, but without the very serious personal financial blow. Are there studies underway in the industry or/and if so, is there information available or has this become proprietary?

JACOBSON: I can't speak for the industry as a whole, but I know that the Wisconsin Blue Cross on an ongoing basis does assess and does attempt to come up with new programs and products that will fill a void. These are in the marketplace, available to the buyer, but the reluctance naturally relates to the cost.

VOICE: It probably comes down to flood insurance. You don't buy it unless you are on the river.



JACOBSON: That is true.

DONALDSON: Dr. Polley.

POLLEY: Are you saying that outpatient care costs more than inpatient care?

JACOBSON: No, sir; I am not saying that. My reference to outpatient care was merely to illustrate that the industry is moving more and more toward providing that type of care as an alternative. And it is providing it because it is less costly too, and it is in a combination to the victim.

DONALDSON: Well, thank you very much, and now if we could ask Dr. Bjarnson, Dr. Graham, and Arlette Grubke. Dr. Bjarnson.

TESTIMONY OF  
DAVID BJARNSON, M.D.  
RHEUMATOLOGIST, MARSHFIELD CLINIC

BJARNSON: We propose to form a multi-discipline clinic for the evaluation and treatment of children with arthritis.

It is important before elaborating on this, to first of all discuss briefly the physical make-up of the Marshfield clinic, as this is very important in understanding our proposal.

The Marshfield Clinic is located near the center of Wisconsin. It is the sixth largest private medical clinic in the United States and presently consists of 140 physicians covering all of the speciality and most of the subspecialty areas of medicine. We are primarily a tertiary referral center, but do act to a certain degree as a primary and secondary center. We service a surrounding area of approximately 250 miles in radius, however, most of our referrals come from the northern half of Wisconsin and the Upper Peninsula of Michigan. Presently there are two rheumatologists on staff with another joining in July, 1976. As indicated, we have virtually all of the necessary specialists, subspecialists and ancillary personnel necessary to conduct a concerted team approach toward a program for arthritic children.

The care of arthritis in our area of referral is currently handled mainly by general practitioners; and most of these physicians have had no special training in the treatment of arthritis. The treatment generally lacks a multidisciplinary approach, and there is no long-term plan for treatment or follow-up. The treatment is further hampered by the general ignorance by the public toward this disease.

We feel that at the Marshfield Clinic we have a unique opportunity to improve the care of arthritis throughout an extensive geographic (mostly rural) area. This can be done through our present lines of referral and by having outreach clinics in areas distant from our Center. The establishment of outreach clinics would be facilitated through computer capabilities available to us which can provide statistical information,

inclusive of the numbers of arthritic patients seen at the Center, as well as their geographic location. We envision outreach activities which would increase accessibility for direct care and serve as an educational experience for community physicians. Additionally, education for community physicians can be accomplished through regular scheduling of conferences and seminars. Education of patients can also be carried out on a local and outreach basis. We have recently hired a full-time patient educator, and anticipate that arthritis education will be incorporated into this program.

Presently, in our area there are no resources for the complete evaluation of children with arthritis, and we, at present, are not seeing the number of patients we would expect. Just over one year ago the Marshfield Medical Foundation announced the planning and development of the Marshfield Comprehensive Child Care Center (MCCCC). Although still in its infancy stage, MCCCC has become a viable entity serving to provide comprehensive evaluation, diagnosis, and critically needed follow-up treatment for handicapped children with exceptional needs. We feel that a program especially designed for children with arthritis could be incorporated into our Child Center services.

Mr. David Draves of our administration is the executive director of the Foundation's Child Care Center and is also the director of the Clinic's outreach programs. I have asked Dave to comment briefly on viable aspects of the Child Care Center and on outreach activities in general, as both relate to our proposal for a program for children with arthritis.

DRAVES: Thank you. I would like to simply hitchhike on some key points Dr. Bjarnson has already made. He talked about our rural setting and he mentioned our unique resources. He also indicated that our Child Care Center and current outreach programs could be used as a part of a concerted team approach to provide services to children with arthritis. I brought along a brochure which is descriptive of our conference of Child Care Center. These brochures indicate not only our manpower resources and referral procedures, but also our interrelationships with other agencies and systems, such as the educational enterprise, and how we are working with those agencies to provide effective follow-up programs for individual children.

In regard to our outreach programs, we currently have over 100 different hospitals and clinics that are participating in a variety of services emanating from our clinic. We have developed a speakers' pool from which outlying physicians may request a topic of special interest to be presented in their own community. We have a telecommunications network which enables us to either send or receive written or verbal communications within a matter of minutes from a four-state area. We have daily contacts with 65 different hospitals and clinics through our reference laboratory service. This also enables us to transport other diagnostic materials such as X-rays. We have compiled a directory of area physicians which tells us, by city and county, what other resources are available. And we also hold clinic hours in various other clinics throughout our area. As Dr. Bjarnson has indicated, we are involved in a number of educational programs for both patients and professionals. We

also have computer capabilities for determining where patients with specific diagnoses are located. This would be a tremendous help in establishing clinics outside of Marshfield for dealing with arthritis.

Thank you.

DONALDSON: Thank you. What are the things that you would need, specifically in the way of resources, in order to do the job you would like to do, as compared to what your resources are at the present time?

BJARNSON: Dr Donaldson, I think probably we need peoples' time. I think we have a lot of resources, but we would need to direct some of those peoples' time into a considerate effort for a program dealing with arthritis.

DONALDSON: And the reason you can't do that at this present time?

BJARNSON: It is financial.

DONALDSON: Are there other questions or comments? If not, thank you. We will now turn to Dr. Graham.

TESTIMONY OF  
DAVID T. GRAHAM, M.D.  
CHAIRMAN, DEPARTMENT OF MEDICINE  
UNIVERSITY OF WISCONSIN MEDICAL SCHOOL

GRAHAM: There is clearly in this country a great unmet need for care of patients with rheumatic diseases. Rheumatology has not fared well, however, in the National competition for financial support. Rheumatic diseases are uncommon causes of death, and their effects are therefore much less spectacular than those of cancer or heart disease, for instance.

As a consequence, research and teaching in rheumatology have lagged far behind research and teaching in many other medical specialties. Only relatively recently has there developed the kind of sustained and widespread research attack on rheumatic disease that promises substantial benefits in the future in the care of patients.

Training programs in rheumatology, both to produce specialists in rheumatology and to increase the knowledge of rheumatic diseases among physicians, generally have also not kept pace with those in other specialties. Some places in the country, of which Wisconsin is one, have far too few specialists in that field. The State of Wisconsin, and the Midwest generally, are in a worse position than many other areas. The number of qualified rheumatologists in Midwest States is woefully small, although a few concentrations of them in large medical centers may make the overall picture look brighter than it is.

Perhaps 45,000 persons in Wisconsin have arthritis; perhaps half of them deserve at least some consultation with a rheumatologist. Currently there are only eight or nine Board certified rheumatologists in the State of Wisconsin. Five of these are in practice, and the rest are associated



with medical schools and have primary responsibilities in teaching, research, etc. It should be clear that we do not have an adequate supply of rheumatologists for patient care, for teaching, or for scholarly activity in the field. Imagine what it would be like in the State of Wisconsin if we only had eight cardiologists, approximately half of them involved in teaching activities, and the rest in practice. While it is true that many cases of heart disease can be handled by the family physician, a significant number do require the care of cardiologists, and were there only eight cardiologists, most people would consider the problem one of sufficient magnitude to constitute something like an emergency. Because people with arthritis don't drop in the streets with myocardial infarction, arthritis may seem less dramatic than heart disease to those who do not have arthritis. Nonetheless, this massive but relatively invisible population is there. I think they need appropriate care and attention, which means that they must have available to them nonspecialized physicians who have a sound foundation in rheumatology, and also highly trained expert specialists.

One function of the specialist, of course, is to treat patients with particularly difficult and complex forms of the illness in which he is expert. In a university medical center like the University of Wisconsin, however, his role is greater than that. The specialists there teach medical students, nurses, physical therapists, occupational therapists, junior physicians in training, some senior colleagues, and others, about the subject matter of his speciality. Few of his students will become specialists themselves; much of his effectiveness lies in the improved care that will be given by the nonspecialists who learn from him. In rheumatology, the number of patients is so large compared to the number of specialists, that it is obvious that most of their care will have to come from nonspecialists.

There are many patients with rheumatic diseases who come to the University of Wisconsin Health Sciences Center. As care is provided them, simultaneously much teaching and learning about management of their illnesses occurs. We now have a very small staff in rheumatology, so that the number of patients with arthritis and related diseases to whom we can offer help is restricted. One gets the impression that the unmet demand for such help in the State is almost limitless. Whenever our capabilities increase, we can of course treat more patients, but the number who would like to be seen, whose doctors would like us to see them, and whom we would like to see, so far exceed the number we can care for, that the unmet demand does not show any perceptible decrease.

Rheumatology as a scientific and clinical area gives every appearance of being ready for explosive growth. It finds itself, however, ready to grow at a time when funds available to support medical research and teaching are shrinking. It missed much of the great expansion in biomedical support that came after World War II, and now is threatened by chronic starvation.

At the University of Wisconsin we feel very keenly our responsibility to foster the growth of rheumatology by developing productive programs of teaching, research, and patient care. As is true in other places, many of

our resources are invested in strong and important efforts in specialties that bloomed earlier, and it would be folly to attempt to diminish them.

It is therefore essential that those who recognize the importance of rheumatology rally to provide the support in money and in public opinion that will permit rheumatology to progress and to fulfill its promise. The root from which that progress springs is a teaching and research program.

DONALDSON: Thank you. Any questions?

VOICE: I would just like to ask if you could elaborate in more specific terms on what might be most beneficial -- what would be the key areas of support that would permit growth in a rheumatology program at the University of Wisconsin in Madison?

GRAHAM: Three or four full-time faculty salaries. That really would be one of the key things. The point is not, you see, that our institution is by any means unwilling to support rheumatology or uninterested in doing so. It is simply that in a time of shrinking funds, we look around for ways to do what we ought to be doing rheumatologically, and we find we don't have the necessary resources to do it very easily. We would like to expand our program very much. There are an awful lot of patients that need treatment. There are an awful lot of health care providers who need education, and there are an awful lot of research questions that need answering.

VOICE: Would you -- just to elaborate a little more -- would you think, if one could get more substantial support for education that this would best be put into the training area for people coming into the field; or would you say it would be most critical for junior faculty who could then grow to become more capable in this field; or where would you say is the highest priority of funding education?

GRAHAM: Well, I don't know that exactly I would want to make a priority list. Certainly, there is a lot to be said for educating physicians right now, trying to do what we can to improve their level of competence; also of nurses and other people. But I think the long run payoff will come from generous funding of academic programs in which fellows in rheumatology can be trained; in which physicians, medical students and house staff can learn enough about rheumatology so that they will know how to treat their patients better and what patients to refer in which research, not only in the mechanisms of rheumatic disease, but also in the best ways to treat rheumatic disease can be carried on. I think that kind of investment, in an academic program will yield very large returns. But we will have to wait five or ten years to see them.

DONALDSON: Well, thank you very much. We appreciate your coming here.



TESTIMONY OF  
ARLETTE GRUBBE  
SOCIAL WORKER  
MICHAEL REESE HOSPITAL, CHICAGO

GRUBBE: My name is Arlette Grubbe. I am a social worker at Michael Reese Hospital. With me is Yvonne Romanes, who is a patient in our clinic there, who has rheumatoid arthritis.

What I would like to speak to today is the issue of inclusion of training and funding for social workers in terms of chronic illnesses and family therapy. We feel that there is a real need to deal with the psychological and socioeconomic problems of both patient and family disabled with arthritis. We believe that within the treatment process itself, where the patient is being seen in the clinic or by private physicians, that their fee would be available to them. We also believe trained counselors should be available to help them deal with the problems of having a chronic illness and to help the families as well, because they suffer a lot in understanding and coping with the problems. Some of the things that arthritis patients deal with are the need for independence and the feelings of guilt and of burden that they are on their family. Families have to deal with financial problems, the emotional problems that are all generated by an illness in the family, especially a chronic one. We would like to see something done about this; that there would be some intervention. We have heard from people today who talked about the parents groups and patients themselves -- and this is a real need.

At Michael Reese Hospital we are attempting to deal with this by establishing group therapy sessions for patients with rheumatoid arthritis. These groups will consist of the patients themselves and the social workers involved. Plus, the rheumatologist, the nurses, and the OT and PT therapists are involved and see them continually in the clinic, so that we can provide some support for the chronically ill.

What I would really like to say is that we would like to see the trained people be available to clinics. And to ensure this, we would like to see funding in training go to social work schools and agencies for this type of training. We would like to see that they be mandatory in a clinic type of setup that we are talking about. We would like to see regional health delivery systems where we would have people intervene at the point of primary medical care.

At at this time I would like Yvonne to respond.

ROMENES: I just wish to make some additional comments to Arlette's remarks. It is vital that advance medical knowledge and surgical techniques be expanded to continually ensure hope for those of us who are arthritics. More funds are needed for further research and to provide scholarships as incentives for doctors to enter the field of rheumatology. Both Karen Stermer, who is with me today in the audience, and I are patients at Michael Reese Arthritis Clinic in Chicago. We are able to be here today as a result of total hip and knee replacements which were performed at Michael Reese Hospital. Karen and I would like to see a cure



for arthritis in our lifetime. Meanwhile, we shall continue to battle the effects of rheumatoid arthritis on our lives.

I wish to reemphasize one of the points made by Arlette. Counseling services are needed by arthritics as well as their families; they must be made available. As a consequence of having arthritis, many of us are denied employment and must cope with anxiety, feelings of inadequacy, and a lack of self worth. These other problems must be given consideration and attention as part of the total picture, not just the physical implications of the disease.

In closing, I would like to make a comment and quote something I heard recently; and I think we can apply this to all arthritics. "I cannot live in someone else's shadow, I must have a place of my own. I need to be, I have the right to be. As me as an arthritic and as all arthritics we have a right to hope for the future."

Thank you.

DONALDSON: Thank you for coming. Are there any questions of either of these ladies? I can assure you the Commission is sensitive to the total patient problem.

GRUBBE: Thank you very much.

DONALDSON: I would ask John Reddy, Janis Pigg and Dr. Treacy to come forward. Originally Mr. John Lovdahl was to testify but I understand he has been hospitalized. And so, on short notice, John Reddy is here. He is manager of operations for Handicabs of Milwaukee.

REDDY: Thank you ladies and gentlemen of the Commission. Mr. Lovdahl sends his regrets of not being here and has authorized me to present his remarks in the first person just as he would have done them.

TESTIMONY OF  
JOHN REDDY  
REPRESENTING  
J. LEONARD LOVDAHL  
PRESIDENT, HANDICABS OF MILWAUKEE, INC.

"Because arthritis is acrippler, the subject of specialized transportation ought to be a concern not only of those afflicted, but to all those concerned in one way or another with the arthritis problem.

As president of Handicabs, a firm specializing in the transportation of the handicapped and elderly, I am aware of the many passengers we regularly transport who have arthritis and are in need of transit services designed to meet their needs.

Since arthritics may grow debilitated over a period of time, they may well find that the "regular taxi" is adequate in getting them to their destinations. If the disease has not impaired walking or has not confined them to a wheelchair, the above mode is convenient and lower in cost than

specialized transportation. If the time comes however, when the arthritic has difficulty negotiating stairs, bending to get into the backseat of an ordinary automobile, or must use a wheelchair, then the specialized carrier is not only a necessity but a godsend. It is important to understand that specialized transportation is not just "wheels", but a driver trained to help with whatever physical limitations the individual may have. Handicabs has long operated under the motto "Door-thru-door service."

With the foregoing in mind, it would seem that the entire spectrum of transportation ought to be a concern of those dealing with the needs of the arthritic. The question perhaps ought to be "what services are available?" "How adequate are such services?" and "How can such services be improved?"

Since I know best that with which I have been personally involved, I might say that in 1958, when I personally needed specialized services to get me to work and to a rehabilitation facility, I found no service available to fit my personal needs. Having had muscular dystrophy for all the years I could remember, I needed what I would call extensive help. I was confined to a wheelchair, needed lifting if I was to go by regular automobile or taxicab. My family, though willing to help, found itself incapable because of circumstances to provide the time flexibility to meet my transportation requirements. It was in the midst of these circumstances that I asked a friend of mine to provide this assistance -- both "wheels" and physical help. He was a young man trying to support himself and two cars, so he was very interested in my proposal. Within a short time, we entered business together.

As is true of many businesses that succeed, "the time was right" -- and so Handicabs rode a flowing trend. That trend was born out of a sudden new awareness (and demand) for better and more extensive community health services. Nursing homes were being built, hospitals were expanding, rehabilitation centers were widening their scopes of operation. Along with this development two other things occurred: 1) the Microbus Van came on the market and 2) Milwaukee began to build an extensive freeway system. The van made it possible to transport passengers seated in their wheelchair (convenience and dignity), and the freeways made the logistics possible to serve a large area with relatively few vehicles (affecting capitol outlay in starting a new business).

Today, Handicabs' fleet consists of fifteen specialized "handicap livery" cabs and approximately 150 school units, all serving the areas' special classrooms. The problem of insurance coverage and costs has been managed by an elaborate "defensive driving program", and maintenance problems addressed through a full service garage facility. But inflation is an ever present problem that keeps Handicabs on its toes trying to provide good, safe service at prices that are often frozen and contained by governmental bodies. It is a maxim that governs utility rate increases that one must demonstrate a sizeable deficit before relief is forthcoming.

Those who recognize the need for adequate specialized transportation services in the community ought to ask the following questions:

- (1) How best can specialized services compete without fragmenting the market and thereby causing an escalation of prices charged?
- (2) What role should Government subsidized transportation play in the community?
- (3) If specialized services are necessary in the community, how can health agencies (such as the Arthritis Foundation) help to make such services more effective?
- (4) How can the health agencies better utilize existing services?
- (5) How can health agencies make it possible for clients to avail themselves of these services through financial assistance?
- (6) Should specialized services be employed for medical purposes also. Or is there a role for specialized services to meet the clients' social needs as well -- and how can the health agency affect this?
- (7) Should the health agency provide its own transportation -- or can the needs of its clients better be served by utilizing services with greater operational scope?

These comments are just a few on the entire subject of specialized transportation services as they apply to given groups of users -- in this case, those who suffer from the debilitating effects of arthritis and are transportation handicapped.

It is my opinion that it be a concern of the Arthritis Foundation that an effective solution to the transportation needs of all arthritic patients be met in the most effective and low cost way possible."

DONALDSON: Thank you. With your 50 cabs, approximately how many people do you service a day?

REDDY: We serve approximately 300; over 700 individual trips. Many of these are round trips; some are one way trips; some are three way trips, from home to one facility, to a doctors office and then perhaps to home.

DONALDSON: Are there other questions? May we just all congratulate you in the work that you are doing.

REDDY: Thank you very much for this opportunity to testify.

MELICH: I would like to ask you are you just in Milwaukee or where are you primarily?

REDDY: We operate a demand response service in a four county metropolitan area of Milwaukee and a scheduled service with 24 hours advance notice in a seven county area in southeastern Wisconsin. Primarily Milwaukee.



TESTIMONY OF  
JANIS SMITH PIGG, R.N.  
NURSE CONSULTANT, RHEUMATOLOGY  
COLUMBIA HOSPITAL

PIGG: The President's Committee on Health Education, in 1973, termed health education, "a process that bridges the gap between health information and health practices." To know and practice self-management is crucial to the person with a chronic disease such as arthritis. All the medicines and therapeutic programs available are worthless if the person does not use them as prescribed. A review of the literature on patient compliance indicates that from 15 to 93 percent of patients do not follow their prescribed regimens (Appendix). The patient and family often need help in making the necessary changes in lifestyle as necessitated by the disease. This requires a health worker in an ongoing and supportive educational role. Information given to the patient, either verbal or written, is not adequate. Patient attitudes and behavior must be affected positively by the information.

In January, 1975, a conference on Regional Medical Program Pilot Arthritis Projects was held in Kansas City. At this conference, the Patient Education Workshop identified important, unmet needs in the area of patient education. In September a Task Force, of which I am a member, evaluated these problems. The Task Force critically reassessed the field of patient education in rheumatic diseases and formulated a detailed plan to take appropriate action (Appendix B). The Task Force identified the factors contributing to the need for a concerted effort in patient education and made specific recommendations:

- (a) Health providers are becoming increasingly aware of the importance of patient education relative to every discipline and role in the management of arthritis. Patient education is no longer considered the exclusive domain of the physician.
- (b) At the present time, and historically, little has been done to carefully examine the concepts, methods and tools of patient education in rheumatic diseases. At this time, no plans exist to meet these needs. Research is needed to look at the concepts, methods and effectiveness of tools used in patient education in rheumatic diseases.
- (c) Essential to the development of a concerted program of patient education is a program of provider education. The concepts and methods of patient education are infrequently a part of medical education in all disciplines. Special attention must be directed to alleviating this roadblock to the effective incorporation of patient education in the management of the disease. Few health care providers, including physicians, are specifically prepared in patient education and adult learning methodology. Only the health educator (a new type of health worker) has academic preparation in this area. With the exception of a few rare individuals in other disciplines, only nurses (and even then not all) receive any training in their basic programs in patient education. Instruction in patient education needs to be incorporated in all basic medical, nursing, and therapy educational programs, as well as provided for in continuing education programs for those already practicing.

educational programs, as well as provided for in continuing education programs for those already practicing.

- (d) Educational materials exist in a random fashion which are of potential use to others. This material needs to be collected, reviewed, and catalogued to save duplication of effort and cost. Of particular concern is the material which has been developed in the Regional Medical Program Pilot Arthritis Projects. There now exists no mechanism to do this. A clearinghouse to provide these functions is needed.
- (e) Materials appropriate for persons with limited educational background, different native languages, family members, parents of children with rheumatic diseases, rheumatic diseases such as systemic lupus erythematosus or anklylosing spondylitis are lacking or inadequate.

It must be realized that patient education cannot be provided cheaply even with utilization of a cost saving measure such as group instruction. Direct third-party reimbursement for patient education cannot be secured at this time for hospitalized patients, even though education is recognized as essential to comprehensive treatment. Formally organized education programs aimed at meeting individual patient needs are even less available to the non-hospitalized patient. Both financial and medical benefits should result from improved patient education. And when education leads to prevention, there are substantial savings for the individual and society alike. This should be a major recommendation of the Commission -- the inclusion of third-party reimbursement for patient education.

Essential to all these recommendations is the need for a way of evaluating the effectiveness of educational concepts, methods, and tools. A beginning tool for evaluating the effectiveness of a patient education program is found incorporated in the outcome criteria developed by staff nurses at Columbia Hospital (Appendix C).

I believe that it is the responsibility of the Commission to undertake and make viable the recommendations I have detailed.

DONALDSON: Thank you. Any questions? I think all of us are very familiar with your efforts and your work. We probably expressed our questions to you many times before, and we appreciate your coming here.

PIGG: Thank you.

DONALDSON: Dr. Treacy.

TESTIMONY OF  
WILLIAM TREACY  
PRESIDENT  
WISCONSIN SOCIETY OF INTERNAL MEDICINE

TREACY: My name is Dr. William Treacy, and I am in the practice of internal medicine in Milwaukee. I am speaking this morning as current president of the Wisconsin Society of Internal Medicine. The Wisconsin Society of Internal Medicine is an organization of some 300 of the practicing physicians in the State of Wisconsin, who by training and practice standards are recognized as specialists in Internal Medicine.

The physician in the practice of internal medicine very soon after starting is quite impressed at how frequently he sees patients with the rheumatic diseases. This was my own personal experience, and in discussing it with many other internists, I find similar impressions, along with the wish that more emphasis had been placed on the rheumatic diseases in medical school and residency training programs.

There is no question that one of the primary ways to improve the plight of the arthritic is to improve the training of the physicians caring for him. In the State of Wisconsin there are between 10 - 20 rheumatologists, depending on one's definition of a rheumatologist, and fully a third of these rheumatologists are in academic medicine not providing primary care to the arthritic. This is in a State with approximately 600 internists and 4500 physicians. It would seem most appropriate for the Arthritis plan of the nation to give high priority to improved training in the rheumatic diseases in general internal medicine residency programs, along with stimulation for the formation of new subspecialty programs in rheumatology. It would certainly be appropriate in the State of Wisconsin.

The second point I would like to make deals with research in the rheumatic disease. The practicing physician frequently finds himself with less than adequate modalities in treating the rheumatic disease. Stimulation of research in the rheumatic disease to improve the situation is very important in any organized approach to combating the arthritic diseases.

In the past two years the Wisconsin Arthritis Foundation has been involved in two programs funded by the RMP which are quite impressive to the practicing internist. One involves an outreach type program where teams of physicians and allied health professionals from the larger medical centers go out into the State and present half-day or day long instructional programs in the care of the rheumatic disease.

The other involves a study of the efficacy of nursing care given to the arthritic patient. I am sure these programs will be presented to you by people better qualified than I to describe them. However, practicing internists in the State of Wisconsin are very much interested in this type of program being continued and enhanced, since they involve instruction and research at the interface between therapist and patient.



Mr. Chairman and Members of the Commission, I appreciate the opportunity to present these views to you as a representative of the Wisconsin Society of Internal Medicine.

DONALDSON: Thank you. Any questions for Dr. Treacy?

BATCHELOR: I just want to assure Dr. Treacy that his concern that attention be given not only to training specialists, but also to the primary practitioner -- this concern is being given careful review by the group of consultants that are advising the Commission on the development of initiation programs.

DONALDSON: Thank you very much. Now if I could call on Marie Heiss and Charles House.

TESTIMONY OF  
MARIE HEISS, R.N.  
NURSING SPECIALIST, RHEUMATOLOGY  
COLUMBIA HOSPITAL

HEISS: My name is Marie Heiss, and I am a registered nurse and I am a nursing specialist in rheumatology at Columbia Hospital, Milwaukee, Wisconsin.

Physicians, including rheumatologists, have too often left untapped -- nursing, as a primary member of a multidiscipline team. The nurse has a natural and unique role. She, more than any other member of the team, has frequent and close contact with the patient -- 7 days a week, 24 hour coverage. This makes it possible for her to recognize the problems and needs of the patient and interpret these to the other members of the health team.

The nursing role also means providing a support of non-judgmental and unhurried environment for the patient. This patient, who experiences a diagnosis of a chronic disease, fatigue, stiffness, pain, fear of crippling or the unknown course of a life threatening disease, has a great need for this kind of milieu. Education and understanding, both for patient and family, are the major focus of the nurses' role. The nurse can also explain the medical program as outlined in meaningful terms to the patient. This explanation is carried several steps further as the nurse both serves as a role model and assists the patient to learn concepts and practical methods for self management at home. She coordinates with the other disciplines for continuity of care, if needed at discharge. The patient's family or significant others also have emotional and learning needs and contribute to the patient's involvement, or lack of it, in the therapeutic program. The nurse assists the family to understand the patient's behavior, his anger, his frustration or his depression and his illness. Teaching is also aimed at bringing the family and/or significant others to awareness of the disease process and the need for reorganization that is a necessity. The nurse also helps the patient

to understand that the family members will go through the stages of adaptation to illness before they can begin to reorganize and give support.

But where does the nurse learn about rheumatology nursing? Basic preparation and schools of nursing is scant. Nursing education, unfortunately, in the past and still in the present, confines a great deal of their teaching of the rheumatic diseases to rheumatic fever; a rheumatic disease that is abating. Nursing medical surgical textbooks are only beginning to expand their sections on musculoskeletal disorders to include more comprehensive chapters on arthritis. The focus is on rheumatoid arthritis, and only a short number of paragraphs are devoted to a few of the other rheumatic diseases. There is little other literature dealing with rheumatology nursing.

I believe it is the responsibility of the Commission to recommend short-term courses in rheumatology nursing, since only nursing should teach nursing,. These courses should require qualified nurses with a variety of specialties; rheumatology, psychiatry, orthopedics and pediatrics.

In the future, working with university schools of nursing, masters programs in chronic diseases with an elective and prime emphasis on rheumatology should be developed. There will also be need for better professional educational materials to be developed for the nurse who wishes to specialize and also for the development of staff nurses who care for these patients. I have only spoken to the care of the inpatient. This leaves for the majority of patients and their families with rheumatic diseases; the outpatient without the specialized care of a rheumatic disease nurse to help the patient and his family to understand and to adapt to his disease. In most cases this is not provided because of a lack of third-party reimbursement for this service. It is, however, every patient's right to this special kind of nursing care.

DONALDSON: Thank you.

VOICE: I wonder if you would comment regarding the problem -- with such little time spent in training nurses in the basic educational program, with arthritis being such a large problem -why is there such little time spent, in your opinion?

HEISS: It is perhaps because -- perhaps the way they look at the rheumatic diseases. If you would listen to the patients and what they are told, like: "take two aspirin and go home and live with it."

I don't think enough emphasis is put on the fact that this is a disease that is serious and that nursing can have some intervention in.

MELICH: I was wondering if you can tell me, with the different types of nurses, in regards to the amount of credit or years they have to train, how do you see the arthritis picture getting into, say, a very short-term where you only have a three year training? Do you feel that would be the last thing they would be involved in; or what do they do with these short-term kinds of training?

HEISS: Well, to begin with I am a diploma graduate. Then, I went on to the University to obtain my degree in nursing. At that time, I think the only thing that they did talk about was rheumatic fever. But what we need to get the nursing schools to do is to allocate a certain amount of time to teach, if it is nothing more than rheumatoid arthritis. I would be happy to start out with that because you can take some of the basic concepts from that and transfer to some of the other diseases like osteoarthritis, systemic lupus erythematosus; and therefore they would have gotten some of the concepts. I would see that very well as fitting in with their programs. But we have to get across to them that rheumatic fever is no longer the disease that is prevalent, but that rheumatoid arthritis and some of the other diseases have a greater need.

DONALDSON: Thank you. Anybody else? Mr. House.

TESTIMONY OF  
CHARLES HOUSE  
PATIENT

HOUSE: Good afternoon, my name is Charles House and I am a rheumatoid arthritic...

There! If that introduction suggests candor as well as the formulated expose considered necessary and proper by Alcoholics Anonymous, so be it. But I must add quickly that, like a regretful alcoholic, I do not wish to be a rheumatoid arthritic because most arthritic patients and most Americans do not understand arthritis at all, for the reason that we have been inadequately educated on the subject and because it suggests the forlorn difference between vigorous youth and the eloquent collapses that accompany old age. In our ignorance, so it seems.

We see ourselves as flawed and declining, with no prospects for cure, not even relief nor rescue nor respite. Our bones continue to deteriorate and so do our high spirits. It is our customary practice to camouflage our mouldering condition from our colleagues and associates. We are ashamed of our affliction and our subsequent decline.

We are poorly instructed. Our public libraries do not have a sufficiency of materials for the lay reader on the subject of arthritis. We read in the newspapers and magazines about whirlwind cures, such as we did only four months ago when a British doctor reported in a nearly sensational manner that he had found not only the cause (protozoa), but a cure for arthritis, a drug called clotrimazole. Two weeks later some few of us learned that the positive statements of a cause and cure was undiluted poppycock -- - untested, except on 12 persons. Further, he was a neurologist, not a rheumatologist and it would have been better for him and for the world of arthritic sufferers if he had stayed in bed.

I am ashamed to be ashamed of my malady, but in the face of public wisdom on the subject of arthritis, I have found it easier to imply that I am neither a wreck nor have I reached the end of my career simply because I am jolted with pain and some skeletal parts are shabby and dilapidated.



Because of this ignorance, I have become coy. I walk with a limp when I am unobserved, but in the presence of others, I stride boldly about my business, to all appearances a hale man of sound limb who has not reached the end of his usefulness.

On one creative occasion, I found myself advancing down the street straight toward a colleague with whom I do not discuss my unpleasant malady. I straightened out my gimpy walk and strode manfully toward him. Then abreast, I was jolted by a sudden and intense pain in one of my wretched shoulders. I was not successful in hiding the grimace of pain as we neared each other, and, my face, I knew, was contorted by the unpleasant shock of pain. My colleague looked surprised at my contorted features and appeared to be seeking, in vain, a reason.

I said, "the damned Packers blew another one!" and, as if that observation was sufficient to bring forth such a monstrous grimace, I strode firmly on down the street, leaving my colleague, no doubt, in awe and wonderment at my fury over the ineptness of the Green Bay Packers.

In such creative ways do I continue the farcial tactics of a wounded man who does not wish to suffer the sympathy and misjudgement of his peers.

To such a body as this, I confess only reluctantly to my fraudulent pretenses, but I call upon you, if you are to help -- please secure a technique to inform the rest of our world that I am not, to all purposes, dead or dying, nor suffering beyond comprehension; that I do not wish to be sympathized with; and that I do not wish to be ill informed and I do not wish to be misinformed.

In short, I call upon you and your associates to consider and reconsider the value of finding a means to inform arthritic victims and the general public of the malady and its mysteries. And if you comprehend the value of such an informational nerve center, you will at the very least enable me and others to end our deceptions and walk off such stages such as this, limping and grimacing as much as we damned well need to, and doing it without being ashamed.

DONALDSON: Thank you very much. I think obviously we saved you until last because we are back to the orientation we should have, and that is the patient. We do have a few people who would like to ask you some questions; so we are not going to let you get off that easy.

POLLEY: I would like to ask you whether the Arthritis Foundation chapter has served any function as a public information center?

HOUSE: I see occasional copies of it on my doctor's table with last year's Atlantic Monthly.

VOICE: I thought somewhere along the line you were going to say that your friend that you met on the street also had arthritis and was keeping it quiet.

HOUSE: I hope he has.

DONALDSON: Well, I would like very much to express the gratitude of the Commission for all those who came and testified today; and particularly those who came and obviously had things they would like to say and didn't have the opportunity. I appreciate your being here. If there are those who would like to submit a written statement for the record, you can believe it will be read and taken into account. And with that, I would declare this session adjourned.

S U B M I T T E D   S T A T E M E N T S

MRS. RUTH BORG  
Poplar, Wisconsin

October 29, 1975

I am told I have osteoarthritis, and about all the doctor said was to take aspirin. But it seems to me that if there were treatments of some kind, that would help. The doctors should know and tell us or there should be some center or place where the doctors would suggest we go for physical therapy or whatever would help.

I would think that the medical professionals, plus the allied health professionals, should go before the Commission.

MRS. J. H. BRIEHL  
Fennemore, Wisconsin

October 22, 1975

One of the reasons I have not attended meetings is that it is too inconvenient to go to Madison or Milwaukee. I think that is one of the greatest problems. If branch meetings could be held, like at county seats, many more could attend.

Also, if your arthritis is not too crippling, all a doctor prescribes is aspirin. Perhaps doctors should be more aware of thiscrippler.

I am a widow of 76 years, still working part time, but my hands and knees are knobby.

My ankles and knees ache so I cannot fall asleep, but am not supposed to take anything besides aspirin (I take the buffered type).

MRS. WILBUR A. BROTZ  
Sheboygan, Wisconsin

October 30, 1975

With nearly a half million arthritics in our State of Wisconsin, it is really uncomfortable to have the disease, when you know that rheumatologists are very scare and mainly are in Milwaukee, and so busy it takes a year to get to see one; if you are badly enough crippled to merit an appointment. A family doctor can take an x-ray, so can an orthopedist; tell you where the pain originates from; give you medication for the pain, and that is it. So now the question remains: What kind of arthritis is it? What are the steps you can take, other than having the pain treated



indiscriminately with medication? How can you prevent some of the pain? What is done to evaluate the effects of the pain killing drugs prescribed? And what is the arthritic's tolerance level, without side effects, for the prescribed medication?

I feel and I know others like me, that an arthritic needs some help between emergency situations when the pain and crippling necessitate hospitalization. My experience has been that after the initial exam by the physician (even at such clinic as the Marshfield Clinic, which also does not have a rheumatologist) as to what joints are affected, pills are prescribed, and at best an exercise program and plenty of rest advised. No further appointments are made to check the efficacy of the medication; the possible side effects, nor the progress or recession of pain and stiffness and crippling of joints.

I realize arthritis is progressive, but I also realize a doctor should be available who can and should check at least every 3 months as to the good or bad effects of the medication, etc., that he has prescribed.

Therefore, what I feel is needed the most for arthritics, like myself, is better diagnosis, treatment and care, such as befits the chronic, progressive illness that it is.

JOSEPH F. BRODACZYNSKI  
Milwaukee, Wisconsin

October 28, 1975

In response to your letter (10-17-75) as to how it feels to have arthritis, will be brief as possible. I am 74 years old, have had rheumatoid arthritis since 1937. I was treated by Dr. Frank Darling and Joseph Regan, orthopedic surgeons, both now deceased. Since 1972 have been hospitalized three times, undergone a series of tests and x-rays which was diagnosed as Feltes Syndromes. Dr. G. Kottke is my physician at present. I have faith in him, but the arthritis still persists. Both of my hands are gnarled and out of shape, can't open them fully, fingers on both hands are bent toward the little fingers, the knuckles of both hands protrude about one inch, the fingers depressed. It is painful and I can't perform my daily chores without fumbling or dropping whatever I try to do. At times I have to rely on my wife to button my shirt, lace my shoes, or pull zipper on jacket. At mealtime I have difficulty in handling the knife, fork, spoon, etc.

It is impossible for me to pick a coin or flat object off the floor. Have improvised on this--I use an old-fashioned button hook to button my shirt, small pliers for the zippers, and a piece of celluloid (if available) to pick small objects, etc., etc. Sorry, but as much as I would like to attend the National Arthritic Commission hearing, I know it will be interesting and educational.

P.S. I want to thank the Arthritic Foundation of Wisconsin for the literature they have sent. I found it informative. Thanks again.

Milwaukee, Wisconsin

November 10, 1975

MRS. JAMES COLE  
Neenah, Wisconsin

October 21, 1975

I have arthritis in the left hip which is giving me increasing pain and difficulty. I would appreciate any information you could send and also can you recommend anyone for me to see here in the Neenah-Menasha-Appleton area.

MRS. W. FASSBENDER  
Sun Prairie, Wisconsin

October 23, 1975

I'm no hand at writing, as I was not lucky enough to have much education, but rheumatoid arthritis hits any type of person. At the age of 47, after having six children and one stillbirth the year before, I was hospitalized with pneumonia. From that disease I went to arthritis. The pain was unexplainable, but after 44 days and much cortisone, I could go home. It took me a year to have my comeback, I was very depressed and tired most of the time. Then it went in a remission until two years ago when our son, 19 years old, got Hodgkins disease. His bout with that was so hard on me that the rheumatoid came back. I've been on three different types of medicine treatments, finally gold shots, and now my doctors have had to stop them. I've again become very depressed, as I'm beginning to feel the future will always be painful. Wish the Foundation could find some kind of a shot that would be agreeable to all humans, and that the body wouldn't react against it. I was next to having ulcers from all the cortisone. It really helped to take pain away, but my stomach couldn't take it. Also, I wish doctors would be able to tell us how we should live with arthritis. By that I mean, what we should eat, how much exercise we should try, how much rest our body should have. If only something could be done, I sure would be happy.

MRS. LORRAINE FERSTL  
Madison, Wisconsin

October 27, 1975

In regards to your article on arthritis, in my experience with it I would say anyone in the medical profession should have some knowledge of the symptoms of it and check for it in patients.

Also, any good rheumatologist should listen to his patient and not be so busy he doesn't have time and then doesn't know he is giving too much of the medicine, and it has unpleasant side effects. These two things happened in my case, and it set me back. I feel I could have recovered to the point of doing things much sooner.

To sum it up--better care and diagnosis is very important.

Milwaukee, Wisconsin

November 10, 1975

WELLINGTON H. FLETCHER  
Washburn, Wisconsin

October 28, 1975

Hope you get this letter in time for the meeting. I am 78 years old, and I am getting S.S. I have arthritis in both hips and in my back. All bent over, but I can still walk with two canes. I want to know what is the best exercise I could take. And what is the best medicine for it? Will doctor have to let you see your chart and x-rays? I get your arthritis paper, and I am glad to be a member.

I asked my doctor for a brace for my back and shoulders, and he paid no attention to me. I would like to see your mobile staff come to Ashland, Wis. There are lots of small towns near. How many people would you have to sign up to get it? Ashland is about 15 thousand.

Here's hoping to hear from you.

MRS. PATRICIA J. FREYMARK  
Milwaukee, Wisconsin

October 29, 1975

When I was struck down with arthritis at age 38, in 1964, I received the quickest education in the world as to pain, suffering, and the realization that the oldest disease in the world is still a mystery to medical science. The only parts of me which had no pain were my eyelids. The hospital, at which I was confined, was at full capacity, so I was given a bed which could be positioned by the use of hand cranks at the foot of the bed. Nurses and aides were so busy that most often they could not respond to give assistance. I was forced to crawl out of bed with the greatest difficulty and with two hands, crank the bed into another position. This was in sharp contrast to a woman patient next door, who was in for a rash condition and was getting oatmeal baths. Her bed was an electric marvel which responded at the touch of a button. My good doctor tried to correct this situation and when he could not, I was released prematurely to the care of my family.

It is frightening not to be able to chew your food, comb your hair, dress yourself, take a step, grasp an object, or lie in bed without excruciating pain. Turning on a faucet, wringing a washcloth, turning a door knob, opening a jar, cutting food, holding a cup to your mouth, tending to yourself becomes a study in pain and frustration. Later, visits to your doctor are equally challenging. Coping with the house door, the car door, and the doors to public buildings are something else. Most buildings, understandably, have extremely heavy doors and are not geared to the elderly or helpless. Lack of public courtesy prompts a person, entering before you, to let the door slam in your face, and the impact will strike your body, for your hands are useless to ward off the blow. While recuperating at home, with family away at work, you find many enemies, i.e., the stairs, doors, windows which will not open to feeble attempts, food containers which are vacuum packed, etc. After months of rest and harsh medication you return to work, only to find that the body which worked wonders for you before is your greatest drawback. The business world forges ahead and has no use for the weak link in the chain. THEY DO NOT UNDERSTAND ARTHRITIS. They tolerate the situation, but do



not like it. My abilities lie in the thought process, more than the mechanics of office machinery. But when you are a woman it is expected that you do both--and for less pay. Fatigue is your constant companion--you barely make it through your working day. This leaves no room in your day for household chores, which is a limited field to the arthritic, nor social activities. YOU ARE TIRED, TIRED, TIRED. The body is rebelling against the medication which is your only relief against your affliction. Pain is always with you, crippling too, unless you've been especially lucky. The disease has deprived you of gainful employment, your savings are gone, and the psychological affects are a blow to one who had been a proud and self-sustaining human being.

"IN GOD WE TRUST," should be the arthritics' prayer, for very few humans have heeded the call. Our Government, which has done so much for so many, is called upon to turn its ear inward to its own suffering, for financial assistance. The fruits of this research will benefit people of all nations and is a far more welcome gift than armaments.

Those in the medical profession must receive specialized training. More Arthritic Clinics are needed. Architects and designers must accommodate those who cannot help themselves. Industry must understand this vicious disease and, hopefully, make allowances, through insurance, for its victims.

The drug industry is the victor. Cost of medication is prohibitive. Something must be done to regulate this.

In line with the clinics, therapy is so important in keeping the arthritic ambulatory. Patients must make appointments at the hospital, which is a problem. Getting off of work, getting to the hospital, etc. I, personally, have received tremendous help from members of the American Massage and Therapists Association (Bergholz Health Center in Milwaukee). (If approved by the AMA, the treatment should be allowable under health insurance.) They are qualified and bonafide therapists, and should be recognized. This should be pursued, under AMA rulings, as it would give much assistance to the already over-burdened hospital therapists.

We need help from many quarters, because we go as far as arthritis will permit. The plea is genuine. We hope it bears fruit.

MRS. P. F. GARCES  
Shorewood, Wisconsin

October 1975

I am happy to know that we finally have a National Commission on Arthritis. Hopefully these public hearings will be the beginning of some much needed help for the millions of arthritics in this country. It seems strange that a disease which has incapacitated millions of people for thousands of years has been given so little attention in this country with all its social programs.

I have been a severe rheumatoid since early 1971. You might say I am one of the fortunate ones because I was able to get to a Rheumatologist early (before I had any serious crippling). With close supervision and

treatment, plus following strictly my home care of rest and "Range of Motion" exercises, I still have very little visible crippling. However, I may be living on borrowed time. There is the constant threat of side-effects from the powerful drugs I am taking. Therefore, my most urgent unmet need is finding a drug which is fairly effective in controlling inflammation and pain, and still has minimal side effects. I'm sure this is echoed by all arthritics, at least those suffering from Rheumatoid Arthritis.

Another immediate need is for more Rheumatologists. I believe there are only three or four in all of Wisconsin. That's only one Rheumatologist for every 100,000 arthritics. Also, finding some way that more low-income people can afford to have the services of experts in the field (rheumatologists). My husband is 66 but cannot afford to retire, mainly because of my medical costs.

I could go on for many more pages but will leave some of the needs for others to express.

Thank you for your consideration.

#### B. GOODRICH

About six years ago I became a victim of arthritis.

In October of 1974 I entered Columbia Hospital as a patient of Dr. Goldman. This was to determine a more effective medication for me and also to evaluate for possible surgery.

Five months later I returned home with new medication, a new total left knee, and new total left hip--I knew at this time that the right hip needed identical surgery. I had this done in July of this year. I have had relief from constant pain and have improved a great deal healthwise since October of '74. I still have arthritis--I found many helping hands in the coordinated efforts of doctors, nurses and therapists.

As a result of my hospital experience, I feel there is a need for some special help before leaving the hospital. Something to cushion the transfer from hospital to home--a big step. This might be accomplished by setting up a half-way room at the hospital.

The room would be furnished with ordinary household things--no trace of hospital living. Gone would be the companionship of a roommate, the higher hospital bed, and the constant services of aides and nurses. I found that skills learned in therapy take on a new dimension when applied to daily tasks. I'm sure others have had the same experience.

This room would be the first step toward adjustment in back-to-home living. First, it would be a true test of one's ability; and second, it would build up self-confidence. Anyone who has suffered physical disabilities plus arthritis pain knows the importance of self-confidence.

November 10, 1975

The "half way room" may be the answer to helping patients over one more arthritic hurdle. No one with this disease will deny that the hurdles are endless and we need all the help we can get.

CARL GRISAR  
Milwaukee, Wisconsin

October 20, 1975

My mother received a letter notifying her of the hearing being sponsored by the National Commission on Arthritis on November 10 in Milwaukee.

I am a trustee of the Village of West Milwaukee, a village of approximately 4,000 people lying between the cities of Milwaukee and West Allis and governed independently. I am chairman of the health committee as one of my responsibilities as trustee. I work with the public health nurse and other health officials.

West Milwaukee has a very high percentage of elderly people and therefore many people afflicted with arthritis. I might stop to say that I also realize arthritis is not only a disease of the elderly; but, also the young may be afflicted. Within a five-block radius where I live I know at least three people who are severely afflicted whereby they can hardly walk. Columbia Hospital is the largest center in Milwaukee but by bus for these people is approximately one and a half hour ride. Sacred Heart Rehabilitation Center is about 20 blocks from Village Hall but not on a direct bus route.

Some views the National Commission on Arthritis might consider are to set up some centers for arthritis close or partial centers at closer hospitals. Another suggestion would be to provide subsidy for ambulances or other transportation to take them to the hospitals, doctor offices, therapy treatment, grocery shopping, or to the Elderly Nutrition Programs. Arthritics need a good diet as part of their treatment program. Many are unable to drive or walk (especially if widowed) or even to climb bus steps effectively.

A third suggestion would be to provide some type of aides to work with the arthritic patients through the public health program. These aides could go directly to the patient's home and help them with meals, household tasks, and therapy, or even go for a walk with them. There are some arthritics who are afraid to walk alone because of the one stage of arthritis where they fall down frequently and cannot get up by themselves.

A fourth point is to keep campaigning against quackery for arthritis treatment, keep informing the public that arthritis cannot be cured but can be controlled and that early treatment can prevent crippling.

I hope that the Commission will be able to put arthritis on the same pedestal with cancer and heart disease. I hope that as much financial backing is given to arthritis as the other diseases so research can be



Milwaukee, Wisconsin

November 10, 1975

carried on and that the cost of treatment will be lessened in some way so that more people will be able to receive help.

Thank you for letting me express some of my views. I sincerely give my support to the Commission and hope they will be able to set up a desirable long-range program. I will follow their developments and will welcome any information they can forward to my office.

Thank you again for your time and attention.

BEATRICE A. HAYES  
Wauwatosa, Wisconsin

October 22, 1975

I have had rheumatoid arthritis for five years. I am 66 years old. The symptoms came on suddenly--severe pain and stiffness in my joints. After six months of treatment by an internist with pain killers and Indocin, I was sent to a rheumatologist. It is my feeling that I would not be as crippled as I am now if the treatment (therapy and medicines) had begun sooner.

My advice to anyone with the symptoms of rheumatoid arthritis is not to delay in seeking help from a specialist in the field.

MRS. L. M. JOHNSON  
Waupaca, Wisconsin

October 21, 1975

I want to put in my letter if it will help any toward getting more and cheaper treatment for all arthritics. I have rheumatoid arthritis, plus a very bad spine, due to the arthritis. I have great difficulty walking, and am now using a cane. I must soon start using a walker. My doctors couldn't be nicer, nor could they do more for me, but what we need in this area--and many areas--is a place we can get outpatient, whirlpool baths, and other therapy, either free for those who cannot pay or at reduced rates for us whose insurance companies are complaining. As it is when I need this therapy, I must be hospitalized for several days and then the balance of the bill is almost more than we can pay. The modern drugs help a lot, but we need more research to find a cause and a cure so the next generations need not have to suffer because they can't afford the treatment. I have had surgery twice on my spine which gave me several more good years. Otherwise I would be bedridden by now. I know there are good State hospitals, but we need to feel we have help at hand when we need it. It is very hard to travel very far, even by ambulance--which I have had to do. The pain is too great. I know there are others who are worse off than me, but just from my opinion, we need more trained therapists in the care of arthritics. And if anyone goes before the Commission, it should be medical professionals and people with the disease. Then they can give both sides of the story--from the doctor's viewpoint and the patient's. Keep up the good work. My husband also has arthritis, and we both take the newer drugs for it.

Milwaukee, Wisconsin

November 10, 1975

LESLIE JACOB  
Racine, Wisconsin

October 23, 1975

One frustrating aspect for arthritics is finding a doctor who is sensitive, whose effort will create a feeling of being helped for the sufferer. The in and out routine--take aspirin--use heating pad--is devastating to the arthritic. Any wonder why we bounce about and often try quackery for some hoped for relief. The medical profession should work to correct this cold indifference among their group. A National effort with private and Government funds to find the cause and cure for this terrible disease must be initiated. To suffer, to become weak and disabled with little hope for help (at least at this point) is the prognosis for arthritics.

We've got to have a more serious effort to eradicate this disease. Hopefully the National Arthritis Commission will provide the impetus toward that goal.

MRS. BERNICE KALISH  
Viola, Wisconsin

October 1975

The unmet needs are: (1) Research, (2) Continuing Education, and (3) Better Care Treatment and Diagnosis.

My husband and I are 52 years of age; he has suffered a great amount of pain since 1946, and last year he had a complete hip surgery; my pain and sick-all-over feeling began nine years ago--it is Rheumatoid Arthritis. In my own case, I alone suspect a connection between my lifelong bronchial infection, rheumatoid arthritis, and cancer, and therefore I strongly urge more research.

Continue education to the public, we warrant understanding. Our suffering is so intense at times, we don't need the "barbed" remarks of well people who are continually on the go and criticize us because we can't do the things well people can. Our pain makes us sick to our stomach at times, even hospital care couldn't help. We force ourselves to go day, after day and if we have a good day we are so happy and thankful we always remember them. Our afflictions forced us to give up a dairy operation we worked hard to build up over the years, putting in 100-hour work weeks (each of us).

Why can't more be spent for research from the Government? Welfare is our country's biggest disgrace, the Agriculture Dept. (relating to ones rural) is now spending two-thirds of its budget on food stamps, of which some is fraud--we couldn't find employees willing to work for us because welfare and unemployment compensation are so high many do not need to work. My point is, can't there be money available for disease prevention, control, and cures? Well people have plenty of handouts (social services).

We've used many drugs for arthritis but still rely on Excedrin daily to keep going. I am praying for help for the many arthritic people, we don't want sympathy; we want help and understanding.

HAZEL F. KESSLER  
Centerville, Ohio

October 29, 1975

I have rheumatoid arthritis. For 29 years it has been a daily battle to stay mobile and ahead of deformities. I have been on cortisone 25 years. I am 57 years old. I also have Sjogren's syndrome. My dry mouth has caused extraordinary dental expenses. I have recently discovered I am getting cataracts on both eyes--possibly due to cortisone. Both my feet and hands have been operated. I have 22 prostheses in my hands. Five weeks ago I had surgery on my cervical spine-C1, C2, and C3 were wired and fused. I had been in a neck brace for 2 1/2 years due to 13 MM sublimation of C1 and C2 with some cord pressure. I also have had many biopsies. I have been on almost all drugs for arthritis up to and including Cytoxan. I was anaphylactic from gold salts, and I have had gross bleeding from the colon.

The early years were horrendous with a baby and young children to care for. I once went for four years without ever sleeping over 25 minutes except when I got some ACTH. Then I could rest for four hours. I had long periods of near total incapacitation. I am furious at this disease and I will never accept it. Being an aggressive person, I was forever getting hung up in the bathroom, doors, etc. I'd get one foot in and then could not shift my weight to get the other one in or out. When my children were very small, they learned to pull me up from a chair, the bed, etc.

I tell you this hoping to impress you and all who will influence future research and treatment. I believe rheumatoid arthritis should be treated as a catastrophic illness. As indeed it absolutely alters the life of its victims and of their families.

I serve on the Board of Governors, Southwestern Ohio Chapter of the Arthritis Foundation. Our Dayton office got a call from a young mother asking, "Is there a halfway house for arthritis?" How I wish there was. We need a place to help such people when they are in exacerbation and life is so laborious.

I have been reading and researching R.A. for many years and have done every reasonable thing I would hear about and I have done everything my doctors have asked me to. Yet the disease progresses. Now giving me residuals. I resent it when I read (even in our literature), "Nobody needs to get crippled nowadays."

I have been in research centers, including NIH, and I see nothing that encourages me. I am in contact with many arthritics and most feel they have been strung along with nothing really helping for long.

Somehow our scientists and doctors who work on finding the answer have got to find a better way to do it. If they have been for years looking for a virus then perhaps they need to find new ways to look for a virus. I think they need to communicate their ideas and findings more readily. In the past, the twice a year meetings of the ARA with a few grants being given leaving many perhaps valuable ideas to go back to their own labs and remain unexplored. Maybe a group of brilliant researchers should get



together and stay till the answer is found. A la the space program when the little town of Huntsville, Alabama, became heavy with brain power of Werner Von Braun caliber. It would help if doctors would listen to their patients. Many doctors are compromised by an intelligent patient.

When I was looking for a surgeon to do my hands, a very well-known orthopedic surgeon said to me, "I'd be a fool to take you on, you know more about this than I do." Another said, "I really don't like to work on someone your age, I'd much rather work on a young person." Recently a rheumatologist said, "It doesn't mean much." He was referring to my sed rate of 68 and my rheumatoid factor at the top of the test. Well it does mean something. I know what it means. He therefore insulted my intelligence. It's a disgrace that this terribly demoralizing disease has gone unsolved. I believe our doctors are smarter than that. I believe they can do it if they just put together the right team!

According to the Arthritis Foundation literature some medical schools in the U.S. have no program in rheumatology. This should be corrected. With one out of ten people having some arthritis every medical school should have a chair in rheumatology. In Dayton, Ohio, at Wright State University, a new med school is in the embryo stage. I have written Congressman Charles Whalen, Dr. Ruppert, Vice Chancellor at Ohio State Board of Regents, and others trying to get a chair in rheumatology (Dayton has only one rheumatologist). They all tell me I need to get private money for endowment. With Federal money going to finance everything, no matter how ridiculous, I don't understand why this is so. I plan to work on it again as soon as I am able.

I am sorry this got so lengthy and for writing it. I tried the typewriter but my neck is not ready. My children are grown up now and my husband is retired. He has been my only help through all these surgeries. I badly need to have work done on both feet but feel I cannot do that to my husband. He has done enough.

I wish it were within my power to build a convalescent center where arthritis patients could stay for awhile following surgery. There would be plenty of O.T. as well as P.T. and anything I could think of to brighten their days.

I am reminded of something one of our chapter presidents said: "If I could, I would give the world arthritis for one day. Then I would jump aside to avoid the stampede seeking to find the answer!" Thank you for your patience.

MRS. ERWIN KIRCHENEERG  
Milwaukee, Wisconsin

October 20, 1975

I am very much interested in the Arthritis Foundation and have been a member for a number of years.

I have arthritis of the spine and hip which has become very painful, and have doctored for at least 10 years for various problems which have led to arthritis and scleroderma.

Milwaukee, Wisconsin

November 10, 1975

Both of my hands are now affected--they have a tendency to become scaley--then crack open and sometimes bleed, so must use lotions and wear gloves a good share of the time. It has also affected the lower lobes of my lungs and the esophagus. The eyes are also affected, inasmuch as it has dried up the lubrication fluids and now use artificial tears for moisture.

I sure wish someone could come up with a solution of some kind to ease the pain and stop the progress of the scleroderma.

Please, if anyone knows of some help, would appreciate hearing from you.

MRS. C. KOWALSKI  
Milwaukee, Wisconsin

October 18, 1975

I have arthritis of the spine, but I also have it in other parts of my body such as my fingers, shoulders, knees, and so forth. My greatest problem is my back. At the present time it is not so bad, but there were times when I was flat on my back, and I was in pain with every movement. I didn't know if I should sit or lay because if I moved from a sitting to a laying position, and vice versa, I was in excruciating pain. As long as I stayed in either position I was okay. Sometimes it would take quite a while and a lot of effort to change positions. With heat, aspirin, and a lot of rest plus a little exercise, I would get over it, but the pain is almost always there; but it was something I could live with it. There was also a time I couldn't use my arm for a month, and I spent \$150 for injections from my family doctor, and it only became worse. I was told of a hot and cold water treatment, and I tried it and got over it. People just don't understand this disease. They think because you're walking around and doing things you're okay, but you're really not. They don't understand that you can't do certain things because you know by doing them it will put you to bed, and then you have to have someone waiting on you. I know I can't do any heavy lifting or pushing or too much stooping, so I have to regulate my work and stretch out my housework, so to speak. Also, when I work part time I do hardly any housework because just getting my clothes and myself ready is enough when I'm working. I even stagger my laundry. When I'm home and not working I try to catch up on my work. I usually work a couple of hours and rest for a while, then go back again. I really would like to work full time because my husband has been off for a year, but even though I was offered a job, I had to refuse, because it would be too much for me even with my husband's help. So you see what a handicap that is.

What I would like to see is that more family physicians would be educated in this field, and also that people like us that have a little money in the bank but are not working could get free treatments, because the money we have we need it to live on, so we don't have to go on welfare.

Also, it would help a lot if there were more commercials on TV about arthritis and show people what acrippler it is. They should bombard the TV with these because I think it is a strong influence on the public and a

Milwaukee, Wisconsin

November 10, 1975

lot of people think it's only an old people's disease. By the way, I'm near the sixties in age, but I've had this trouble since my early forties and even had some bad times in my thirties.

H. E. LUECKE  
Appleton, Wisconsin

October 24, 1975

I am a male, 59 years of age and have had arthritis for 27 years. I, like many arthritics, had to give up a lucrative position and an active social life at age 47. I am more fortunate than most as I was still able to raise and educate my three children with the help of disability insurance. I am also able to get free treatment from the VA hospital.

However, those of us living on fixed incomes find it more and more difficult to cope. We can not go to specialists in the field of rheumatology or orthopedic surgery. Physical therapy is very important to an arthritic and should be made available to him as soon as possible. Aids such as crutches, wheelchairs, and other devices should be considered in making the arthritic more comfortable.

I fail to see why some kind of fund cannot be made available to directly benefit the individual. Mental and physical frustrations are a part of life for the arthritic. If they knew that people cared, it would do a lot to ease the frustrations.

KARL MAIER, JR.  
Milwaukee, Wisconsin

October 26, 1975

I am 73 years old, in excellent health, and have recently developed an arthritic condition in my neck. The condition is not painful during the day, and I am aware of it only when I endeavor to turn my head. At night it becomes quite painful when turning in bed from side to side.

My internist suggested taking aspirin to alleviate pain, but I was more interested in some form of physical therapy which might lead to a cure or stabilization. I have had diathermy, ultrasound, and traction. Each seemed to give some temporary relief for varying limited periods. Fortunately, x-rays taken at six-month intervals have shown no progression over a period of three years.

I appreciate that arthritis is in the general category of degenerative ailments and that cure through medication would probably require discovery of the fountain of youth. I would hope, however, that over the next few years increasing attention might be directed to physical therapy so that persons who were willing to follow a daily regimen of some kind could stabilize the condition and live more comfortably.



Milwaukee, Wisconsin

November 10, 1975

DONNA J. MANNING  
Wyoming, Michigan

November 4, 1975

I am most enthusiastically in accord with the Michigan Arthritis Act.

As an arthritic myself, I know what this could do for other arthritics.

We need all four areas very much but I would like to concentrate on two areas for right now.

1. Patient Services--I would like to see some help, in some way, for our people that are on limited incomes, to be able to have the care and medicines they need. I am very fortunate indeed in that my husband works for General Motors and we have a very good drug program through Blue Cross-Blue Shield but there are many people not as fortunate as I and I fear that they don't always get the proper care or medicine they need to combat this miserable disease. It's bad enough to be in pain every minute of your life, but to have to worry about doctor bills and prescriptions too, just isn't fair.

2. Public Education--We have to do something more than we are doing already to make the public aware of not only what we are trying to accomplish for the arthritics but of arthritis itself.

I know from my own experience that unless you or someone you know has arthritis you don't really pay any attention to it. Before I came down with the disease, I hadn't heard nor did I know anything about the disease. I'm sure there were news articles, volunteer groups such as ours for the arthritic, but because it didn't apply to me at that time, I didn't take any notice of just what was going on.

Like the old story--it seems we will have to hit the public on the head to get their attention and then tell them about Arthritis. We definitely need public awareness.

I think sometimes our doctors fail in that they are either not informed of our volunteer groups and the patient services we try to have, or they just neglect to tell their patients about us.

3. As for Professional Education, we do indeed need that. With my volunteer group I have heard many, many times people saying, "My doctor says I have arthritis but I will just have to learn to live with it." Living with arthritis (even on medication) is one terrible experience, let alone living without medication.

4. Last but certainly not least is our Research Programs.

Without the research that goes on, we arthritics would certainly feel doomed! Through research we feel we have hope, that we are not being committed to a life sentence of pain and even if the answer comes too late for us now, we still have the hope for our children and their children.

Milwaukee, Wisconsin

November 10, 1975

There is pain and agony when we think of our children having arthritis. I know, because my son who is only 23 years old has gout (which is under control) but this is the way my arthritis started out when I was 36 years old. Will he be committed to a life sentence too?

I pray not!

MRS. HAROLD NAYES  
Chippewa Falls, Wisconsin

October 30, 1975

I would like to submit a statement in regard to the National Arthritis Commission Hearings.

I am a 45 year old woman who was diagnosed as having rheumatoid arthritis at the age of 18. I am still patiently waiting for a cure to rid myself and others of this pain, etc. I received an artificial "total knee" at Mayo Clinic 3 years ago and will need another one soon if a cure isn't found within the very near future.

I am looking forward to the day when this "old" disease may be conquered instead of just managed. I feel my needs have been met well in the last 27 years by the following: Having the same local doctor until his retirement this year. A wonderful understanding husband and two helpful understanding sons. Receiving the Arthritis Foundation News papers since the 1950's has been extremely helpful by keeping me posted on the latest treatments etc. After I learned all I could about the disease and was reassured by your pamphlets that I was doing everything to help myself, then I learned to live with it, slowed down, rested more, etc. Artificial joints are wonderful but they are not the real answer.

This summer I attended a series of meetings at Sacred Heart Hospital in Eau Claire, Wis. sponsored by your foundation, I think? It covered all phases of treatment for arthritis. I was again reassured that there is no new sudden cure and rest is really an important factor in treating a flare up. I will, as a result of the meetings, no longer feel guilty for taking an afternoon nap when I feel it necessary but will continue to hope and wait for a cure.

I can't say enough good about your Foundation News paper. Just knowing there are so many people working on the problem is reassuring. We certainly don't need to hesitate to ask for funds for an organization that has already done so much to inform and help so many people already.

There is a definite need for treatment centers all over the state and nation so the people can get to them without an additional burden on the family or friends that must travel long distances to get treatment while waiting for a cure. With 1 out of 4 families being affected is proof that the need is there. I am hoping someday to be free from this pain through research findings. There should be no hesitation on the part of our legislators in funding money for the National Arthritis Act because it affects so many families in the nation and your organization has proved itself worthy of handling funds entrusted to you and could do so much more with proper funding from the National Arthritis Act. I hope others can be

Milwaukee, Wisconsin

November 10, 1975

spared this long term pain, etc. by a cure being discovered soon. It's only money, you know.

ADRIENNE NELSER  
Madison, Wisconsin

October 30, 1975

From discussions with my arthritic patients and nursing staff, I'm listing the following as urgent needs of arthritics living in their own homes:

- (1) Homemaker or health aide services
- (2) Housecleaning help. Arthritics need these people, but once located, more difficulty with payment
- (3) Meals brought to the home
- (4) Education of family

EDWARD J. POKORNY  
Milwaukee, Wisconsin

October 29, 1975

More research and information should be given to arthritis. I have been taking aspirin (and other medication) every day since 1961. The possible adverse side effects of drugs should be posted on the medicine containers given the arthritics.

I now have leukemia and have bone marrow problems which could be caused by the aspirin I took for the past 14 years. Other arthritic individuals I know also have bone marrow problems.

MRS. HENRY RAVEN  
Sheboygan, Wisconsin

November 5, 1975

My suggestion would be to have a place in communities where we arthritics could go to talk over our problems with someone who understands arthritis--such as the "Living Adjustment Group Program" which was described in the October issue of your paper.

And if need be one could get financial support and be independent. To be dependent on a husband who doesn't understand and who resents and ignores an illness of any kind leads to many stresses and strains in everyday living, which I think an arthritic should be without.

My letter does not apply to all husbands, of course. I understand that people vary in their attitudes.

My letter refers only to my unmet need. To cite a case--I have a sister-in-law who has had arthritis for 30 years, when she became immobile her husband cared for her every need--she is transported from bed to



wheelchair from wheelchair to car seat by a device such as a crane which he had installed on the car top. She wears a canvas seat and strap with a hook, and in this way is lifted to and from. Also gets to go on the golf course with him.

BETTY F. ROCKABRAND  
Oconto, Wisconsin

October 23, 1975

I will attempt to answer the letter I received recently from the WAF office in Milwaukee.

As a "victim" of rheumatoid arthritis since 1961, which I contracted at the age of 39, I have been through many trials and tribulations battling this very cruel condition.

In my own case it was a severe blow to receive this diagnosis, as I had always been a very active young woman--sports, gardening, etc. My husband was doing well in his work--had reached a manager's position with a utility company. We had three growing children--two daughters ages 13 and 10, and a young son almost 5.

I won't go into all the problems I had--there were many. I do think the main problem from the very beginning was my extreme fear and anxiety of what the future held for me. I approached everything from then on in the most negative way. My whole outlook became very bad. Eventually this all took a sad effect on my family. Our communication broke down drastically. I think if we could have had professional counseling as a family, we could have avoided many of our problems. We all made mistakes--mostly due to our ignorance of the dreadful condition and the devastation it can cause to the person involved.

Therefore, I feel that the most urgent and unmet need of the person who becomes afflicted with arthritis, especially if she is a young wife and mother, would be to have her doctor refer her and her family to a good counselor. I believe he should stress this most emphatically--otherwise, the risk of the breakdown of the family unit is almost certain--even though they were a stable and close family unit previously. To me, a basic need of the arthritis victim is to have the support, encouragement, and love of their immediate family members. By that, I don't mean they should wait on the person and treat them as a cripple. I mean to try to treat them as they were before. As the arthritis becomes progressively worse and the pain more chronic and severe, it seems most imperative to have understanding between the arthritic and her/his immediate family.

I hope this letter will be of some help to you.

Milwaukee, Wisconsin

November 10, 1975

EUNICE A. RUEPPEL  
Green Bay, Wisconsin

October 23, 1975

I have cared for my 89-year-old aunt for the past two years and seen her suffer severe arthritic pain. I have had hip surgery on both hips -- the first, Matchett Broun, has not been as successful as the Charnley in the other hip so I use a cane.

People with arthritis require help if they are to continue living in their own homes. This means housekeeping help, yard work, etc., to get to the cause of their suffering. We need an early diagnosis of arthritis, with new treatment to obtain this, we need to spend more money on research. The information obtained should be channeled to doctors and others, through education and especially to professionals in training.

With the help of professionals and community service and funding agencies, we trust that the Commission will be able to implement programs to meet the needs of the arthritic.

BEATRICE M. STAHL  
Milwaukee, Wisconsin

October 21, 1975

I think there is much to be done regarding treatment of arthritis (particularly my type) and controlling it or correcting it! Mine was diagnosed as "osteoarthritis with marked degeneration of the cervical spine" the latter part of November 1973. This diagnosis was obtained through one X-ray, however, I was referred to two physiotherapists at two different hospitals, an orthopedic doctor, a neurosurgeon, a rheumatologist plus a doctor who was recommended to me by the Arthritis Foundation, and an osteopath (this I arranged myself); in addition, I have had numerous X-rays that could eventually prove detrimental to my health! I have very little pain, if any, and continue to work full time. It is difficult for me to hold my head high and straight, and difficult for me to turn to the left (to the right is no problem). I have been doing certain exercise (some on my own) and have a neck traction device at home. Sometimes, at this point I wonder if I would have been just as well off by never going to a doctor for this condition, as it was not until friends of mine asked me if I had a stiff neck that I noted anything at all--and I didn't realize I had osteoarthritis at all until my visits to various doctors! I also wear a soft cervical collar at the office and at home.

I believe it is time for doctors to consider something other than drugs and exercise for my particular type of arthritis. I think what we eat and vitamins deserve extensive study -- rather than being scoffed at! And I firmly believe that ALL DOCTORS SHOULD STUDY ONE SET OF X-RAYS INSTEAD OF HAVING A PATIENT UNDERGO SEVERAL SETS! It is difficult for me to believe that nothing further can be done -- that it is "up to me" to hold my head high; I also am now troubled with high blood pressure and was told this was due to tenseness due to my condition--yet, prior to my running to various doctors, undergoing numerous tests, x-rays, physiotherapy, my blood pressure was just about constant at 120/70. Drugs have not helped me at all--I discontinued Indocin several months ago -- and there is not the slightest difference, therefore, it is almost

November 10, 1975

conclusive that my type of arthritis cannot be helped with drugs--as it is primarily stiffness and awkward turning. Isn't it just about time to devote more study to vitamins and what we eat? I certainly would also appreciate it if someone could advise me in plain English why the Arthritis Center in Desert Hot Springs, California, is not "recommended by the Arthritis Foundation" ...other than they do not have a "rheumatologist on the staff." What difference does this make? I was told by them by letter (sent them my medical history that I compiled myself) that mine is the type they have been able to cure or alleviate--yet, no one will check this out for me. Has someone from the Arthritis Foundation been there as a patient to see just what they are doing? Please--have someone check this out and give us definite reasons rather than "not recommended." And, don't you agree that x-rays can be hazardous? I happen to feel that vitamins can be helpful and I wish you would begin a thorough study on this; also, the food we eat! And couldn't spas be beneficial? We seem to concentrate so much on discovering new drugs and I believe what we eat and drink--and lack of vitamins could have an important bearing!

MRS. RAYMOND THORSON  
Elroy, Wisconsin

October 29, 1975

I think we should have better care, treatment, and diagnosis in our arthritis. Something should be done so we wouldn't get so crippled and suffer such pain. So little is done through the public for our disease. Also, a person with the illness should articulate before the Commission.

MARIA TRACHLUH

November 1, 1975

I am not good in English writing, as I educated myself after coming to this country, but hope these few sentences which are written from my own experience will be some help.

Arthritis is one of the most painful sicknesses. My believe is to get the best medicine any person can take without side effects to relieve the pain. Specially trained doctors to perform the operations on hips and joints. To help older people and children and show them the best possible way how to live with arthritis. And nurses who have some special training in dealing and nursing arthritis patients.

MRS. DAVID BARTELT  
West Allis, Wisconsin

October 28, 1975

As a woman with osteoarthritis, I feel there is much need for research and information on arthritis. There has not been enough research done on the cause and treatment of arthritis. This should have top priority.

More information on arthritis should be made available to the "Family Physician." This is the first place a person goes for help and the place where the least help is available. I don't know how this can be done; perhaps through medical journals or brochures.



The Arthritis Foundation is doing a wonderful job with the classes at local hospitals, but they cannot hold them often enough to take care of the many people who need the information given there by the therapists. More clinics of this type should be offered at many more locations.

More information should be made available to the general public to make people more aware of arthritics and their problems. The series in the Milwaukee Journal was an excellent example of this. If the newspapers could be interested in publishing more of this information, it would be a big help.

I feel the medical professions and allied health professions should present our views to the Commission.

GERTRUDE H. BOWMAN  
Oshkosh, Wisconsin

October 27, 1975

The unmet need regarding Arthritis, in my opinion, is that enough research is not being done, at least I have not heard too much about it. There is not too much written in the American Journal of Nursing about the Arthritis.

I am a graduate, registered, professional nurse, and have cared for both young and old with this affliction. I also feel that better care, treatment, and diagnosis is indicated in many of these cases, but due to lack of knowledge, routine care is instituted.

Continuing education of the professional people and the lay persons is indicated with a down to earth language which all can interpret, understand, and put into action.

The articulation of the needs of the Arthritic should be assigned first to the medical professional and the allied health professionals. People with arthritis certainly would be an asset. Labor and industry representatives should also assist in the program, but I do not feel that service agencies or community funding sources would be interested enough, because of their overload of other services.

ADELINE H. BRANDT  
Appleton, Wisconsin

October 23, 1975

Will try to give you some answers to the questions you asked for on your "Guidelines to Preparing Statements for the National Arthritis Commission Hearings."

What are the unmet Needs: I feel there could be more on research and continued education.

What should be done to meet these needs: Research laboratories and doctors as soon as money is available.

Who should articulate the above before the commission: Medical professionals and people with arthritis. Community Service agencies, public community funding sources, public and private.

Many years ago I was on the Arthritis Board in Milwaukee and I think I was called for about two meetings and then it seemed nothing more was done. I lived in Milwaukee at that time and was Mrs. Fred H. Brandt. Mrs. Kloetche was on the Board at the same time, and our names were on the letterhead. I think it must be about 25 years ago, as I live here nearly 20 years.

Now I am an arthritis patient, and two years ago had total hip replacement on both my hips. Had surgery 11 years ago at the Mayo Clinic and at that time had a ball and pin in the left hip, and a cup in the right, but this time I had both done right here in Appleton by Drs. Sargent and Gunderson. I still have troubles as my knee and foot have become arthritic, but at least I did get off my crutches after 11 years. I have spoken with Mr. Torinus, as he too had this same surgery and was able to throw away his crutches. While I was still employed I had a lot of advice from folks with whom I came in contact, and all of it was "quackery." That is why I feel there should be more education for the general public. Thank you for letting me express myself.

MRS. ARTHUR BROWN  
Siren, Wisconsin

October 24, 1975

This letter is written to describe my own disability due to arthritis, and also as medical records clerk in a nursing home.

The onset of arthritis, in my case, was sudden, following a strain of my left thumb. For over a year I have been unable to do any "wringing" action--hand laundry, jar lid removal, lifting objects with my left hand, without pain. Advice from physician is to take aspirin to relieve pain, and if it becomes less bearable, cortisone injections will be considered.

As medical records clerk, I can report that 20 percent of the residents have a form of arthritis in their primary diagnosis; but it is probable that at least 50 percent of them experience arthritic pain as a lesser part of their disability. Early diagnosis and treatment would have made life much easier for these older people.

The need for education and awareness of the symptoms of onset should be as well publicized as is cancer and heart disease. Also, more publicity should be given to continued advances in surgery for arthritic patients.

Only indirectly have I known of surgery being recently performed on one of our local residents. Her hands and feet were so badly crippled that she could use her hands for very little, and she could barely walk. This surgery was performed to straighten the fingers and toes. If this surgery is being done on a wide scale, why isn't the general public made aware of it?

I feel that further research to provide relief from this crippling disability is the most unmet need, but greater publication of the facts of the disease and what is being done to overcome it would serve another need.

MRS. ADELINE N. BRUNKE  
Madison, Wisconsin

October 29, 1975

I am unable to attend the public hearing at the Marc Plaza Hotel on Monday, November 10, because I am a victim of rheumatoid arthritis who is dependent on others. Therefore, I hope my letter will suffice.

I have had rheumatoid arthritis for 20 years; had a remission for about 2 years at one time, but for the past 5 years or so I have become quite disabled and somewhat deformed. Having been employed as a Secretary and Office Manager for approximately 38 years, I found it necessary to retire because of disability approximately 3 years ago. Because my disability has affected my hands and feet, there is little I can do in the way of work, caring for myself, and keeping occupied. I must use the wheelchair if I need to walk any distance or stand for any length of time. I can't operate the chair because I have no strength in my hands.

My most urgent need, and that of all the other arthritis victims, is to find a cure. More money must be devoted to research--good honest to goodness research, and I believe the Government should pay for most of it, since it is of benefit to everyone to find a cure. No one knows when it may strike them or someone near and dear to them. I understand the Government is now providing large sums of money for cancer research. Arthritis, while it is not a killer, is worse in so many other ways.

Further, arthritics need hope--they need to be told that research is going on--how it is coming along and where it is being done. The public is little aware of the silent suffering that goes along with having rheumatoid arthritis. The pain, the discouragement, and depression resulting from it is too often referred to by doctors and friends as chronic complaining or neurosis. Most arthritics, although deformed, appear to be in good health and too often get little sympathy and help from friends and relatives for this reason.

A health spa that catered to arthritics would be very helpful I believe --at least in my case. Trying to do contrast baths on both feet and both hands, and then doing exercises to keep the range of motion in all of your joints day after day and sometimes twice a day, gets hard to cope with when you are on your own all the time. It could help to go where others are doing these same things with some outside help.

Another problem we have mostly is a lack of strength in our hands and fingers. Entrance doors to public buildings, stores, etc., are almost impossible to open without help from someone. Most of the time when you go to a restroom in a restaurant you hope and pray someone will come in so you can get out, because you can't push the door open or pull it open by the handle.



We need to be able to purchase clothing that we can handle in dressing ourselves. We are so limited in what we can wear for this reason. Proper fitting shoes are an almost impossibility to find. I don't know how you could help in this respect, but it is a problem to be dealt with.

These safety bottle caps are another problem for arthritics. Most any child could open them if worked on a while, but not an arthritic.

What it is like to have arthritis probably is different with each individual, but for me it is an agonizing, painful, crippling disease that has sapped all the strength from my fingers and hands.

I believe the two most important needs at the moment are more research to find a cure as soon as possible, and education of the public on the disease. Anything that you can do for us will be gratefully appreciated.

LYDIA DEAUCHAMP  
Madison, Wisconsin

October 28, 1975

I have been a rheumatoid arthritis victim for 40 years, becoming more handicapped as time goes on.

I feel the unmet needs certainly are research, diagnosis, and information. I have had therapy, which I thought helped at the time. However, hydrotherapy is excellent. But most of all, understanding by the public would help immensely. Those who should articulate before the Commission should perhaps be medical professionals, allied health professionals, and people with arthritis.

Most doctors say you have to learn to live with it--but no one knows the pain one endures day after day except the victim.

JOHN C. DeYOUNG  
Randolph, Wisconsin

October 27, 1975

I am 46 years old and have been disabled for two years now with arthritis. I have four children and would like very much to be able to work and support my family.

I think much more should be done in research to find a cure for this. In comparison to other medical problems like cancer and heart trouble, far too little is done for arthritis.

With no insurance and living on a fixed income, it is hard to meet the medical costs for treatment and care.

I believe if the United States Congress knew how people with arthritis live there would be more funds for research and medical help for the people and to find a cure. Thank you.

VERA H. ELLEN  
Cudahy, Wisconsin

October 1975

As an arthritic, I would like to see more research done for a cure, or at best a relief medicine that would have no bad side effects.

There should be more sessions on "self-help for arthritics" such as I have just attended at Trinity Hospital. That course gave me many suggestions for living with my problems. It was truly valuable.

CHARLOTTE ENNICON  
Berlin, Wisconsin

October 27, 1975

In behalf of myself and daughter, who is greatly affected by arthritis, and all 460,000 more in State of Wisconsin, I sincerely hope some help can be found. I am old with very bad knees, hips, and back but to the many that are so crippled can't walk, hands in knots so they can't even write hardly sign their names and in terrific pain, I hope some help can be found. One uses all their funds what is left for them I hope the Foundation at their meeting will be able to solve some relief. It is not a pleasant outlook to sit (if you can sit) and just stare, shuffle if you can be on your feet at all. Where can one go from there. I would like to see or have more research, development, better care, treatment, and diagnosis and training.

As for who should articulate the above, I am not so good a judge, however I think the allied health professionals on research, medical professionals, better care treatment and diagnosis, information, community funding source, public and private.

So much is done for many other projects, some not necessary so much to for people in other parts of the world. So why not Congress do something for all 465 thousand so we can work and live our lives without being crippled.

RUTH O. FALTER  
Janesville, Wisconsin

October 26, 1975

Early detection--before the fact rather than after the fact--would be a great help to the alleviation of pain to the patient. In my own case a period of over six months went by before I was informed that I had rheumatoid arthritis.

Much more research would have to be done to detect arthritis in its very early stages, in order that a patient may help herself, or himself. And more money allocated for this purpose.

Our Wisconsin Foundation does an excellent job of keeping us informed of progress in the treatment of arthritis, and the developments also, by letter and meetings.

Personally, I want to know "why"--is it nutrition, and if so, why do no other members of my family have it? Is it inherited somehow, and can it be overcome? Is there a lack of some element in the body which could be replaced by vitamins or minerals? In any event I decided never to give in to it, but to keep active and live with the ache.

Let the Arthritics speak for themselves! And the Medical Professionals! And let them tell it as it is, not the way elected officials want it!

MARY LOU FRAZER  
Oconomowoc, Wisconsin

October 27, 1975

To me, the most urgent, unmet need of a person who has arthritis is a cure; research, leading to a cure, and what causes rheumatoid arthritis (as well as other types) in the first place.

Is it a virus, infection, blood defect, how do we get it? Or is it a mix-up of the genes, something we're born with and has to have the right circumstances to cause a flare-up?

Is it inherited? If so, what can I do for my sons while they appear healthy, to prevent the start of arthritis? (Years ago, my mother was told she had rheumatism.)

Or is it something in our makeup, our disposition; are we all the anxious, nervous type? The perfectionist--or why does one twin sister develop arthritis--the other does not.

We so much need a cure for those who have arthritis and to prevent new cases in the future. We want to be useful people, to be able to work, to make our own way, and live normal lives.

Millions of people are hoping and praying for this day.

FRED W. GETTELMAN  
Wauwatosa, Wisconsin

October 28, 1975

At the request of our local Wisconsin Foundation chapter, I will try and describe my bout with arthritis.

About five years ago I found out I had the gout in the left big toe. It wasn't discovered on the annual physical exam, and only when I thought I had broken the toe did another doctor in the clinic identify the problem--benimide was the solution.

About four years ago I had severe pains in the right groin area and finally was sent to an orthopedic man. Osteoarthritis of the right hip. Checking around town for a good orthopedic surgeon, Dr. Bruce Brewer replaced the hip three years ago. The results were wonderful and people were amazed, and several had their hips replaced. I cooperated with Dr.



Brewer's study at the Veterans' Hospital at Wood, Wisconsin. This spring (March, April 1975), I had pain and swelling of the hands and feet, mostly on the left side. A two-week stay in the hospital showed nothing extraordinary, but a suspected case of rheumatoid arthritis.

My internist, Dr. Royce, got in touch with Dr. Bernhard, an arthritis specialist, and in August--three weeks in the hospital--tests, x-rays, etc., it was a form of rheumatoid arthritis. Pills didn't do the job, and we went to the next step.

Today--on 16 Ascription--2 Indocin and 50 mg. gold shot. After 10 weeks and am coming along good, and hope at the end of 26th week will have the problem solved. Yep--the other hip is wearing out, but we'll watch it and replace it when the time comes. A 60-year-old grandpa can't be made into a 30-year-old youngster, but he can be repaired to keep going.

Now I'm on about every list for contributions that is available--heart, cancer, epilepsey, March of Dimes, hospitalized vets, Indian funds, and about 50 more. In most cases, all good causes, and I contribute.

I think heart, cancer, and a few of the others have had enough publicity and raised funds for research and rehabilitation that they can carry on on their own. Arthritis needs this boost, and programs should be designed to aid the Foundation. Memorial contributions, wills, fund raising events, and the plight of the arthritics brought to the public attention. Research, dissemination of information to both the medical profession and layman on progress being made should be the goal.

Sorry I can't attend the hearing in Milwaukee on November 10th, but "Doc" Bernhard and the rest have me in good enough shape to get to Idaho and see my son and daughter-in-law.

LAVERNE GOLOB  
West Allis, Wisconsin

October 28, 1975

Arthritis is a disease that affects millicns of Americans, yet we're not doing very much about it. It is second only to heart disease in disabling industrial wrkrs, but too many people forget that it is a serious disease.

One-fourth of the medical schools in the United States do not have special programs on arthritis for their students, yet in Canada, every medical school has a bona fide arthritis treatment and diagnosis center.

As one of the 50 million suffers of this vicious disease, becoming more disabled as time goes on, I feel that there is a definite need for expansion of arthritis research training, public education and treatment activities, and arthritis treatment centers should be set up around the country. Such action is long overdue, and it should be put into effect as quickly as possible.

MRS. ARTHUR H. HANSEN  
Green Bay, Wisconsin

I am a victim of arthritis especially in my finger joints and in my spine. My doctor finally fused several joints in my fingers to relieve the pain but what to do for an aching back! Medication helps but little, and I just have to live with it.

I would like to see more research activity to rid the body of this painful arthritis.

ELELYN HESS  
Cincinnati, Ohio

November 10, 1975

"How To Do Better With What We Have"

With a few exceptions, the cause of most of the rheumatic diseases is not known at present. It would appear then that a first priority should be intensive research to find the causes of these disorders. In the final analysis, only by finding the cause can we control and, hopefully, cure and eliminate these diseases. Without research, none of the advances in medicine and science which have benefited us all so greatly would have come about. Although such work is of the greatest priority, this does not mean that improved care of those with the disease and methods of case finding and prevention cannot also be given every priority. These aims are not mutually exclusive, and there should be every opportunity through the National Arthritis Act to seek the cause and at the same time care for the patient.

At the present time, a great deal of information is available in the United States on many aspects of the rheumatic diseases but is difficult to obtain and to use in the best possible way to help in our search for the cause and to provide better care for the patient. Indeed the first requirement of such an information system is not yet widely accepted, that is, a common language and a uniform terminology so that we may all understand each other.

It is for this reason that very wisely, the National Arthritis Act of 1974 states that "as soon as practicable after the enactment of this section, the secretary . . . shall establish the arthritis screening and detection data bank and 2) the secretary shall provide for standardization of patient data and record keeping for the collection, storage, analysis, retrieval, and dissemination of such data in cooperation with projects under this section and Centers assisted under section 439."

Since the American Rheumatism Association Computer Committee originally presented evidence to the National Arthritis Commission in May 1975, it has become even more obvious that we are not making the most of what we have. Presentations to the Commission, medical meetings, articles in the medical literature, data presented at the American Rheumatism Association Second Workshop on a Standard Data Base in September 1975, all point to poor integration of the information which is potentially available for the care of rheumatic disease in the U.S. The American

Rheumatism Association has been in the forefront of the recognition of this information gap and has, during the past few years through its computer committee and through its two workshops on the Standardization of a Data Base which would use a uniform descriptive vocabulary, endeavored to provide the leadership and the experience which can be made available for those important sections of the National Arthritis Act which recognize this important need. This need was also recognized by the Commission with the formation of the data work group. The report of this group will be available for the National Commission in the very near future.

The quite modest recommended budget, which ranges from \$2.5 million in year one to \$5 million in year 4, represents in our opinion, a tremendous bargain which will allow us "to do better with what we have" and, in so doing, provide important clues to the causes of these rheumatic diseases and at the same time improve patient care throughout the United States.

HARLEY HOPP  
DePere, Wisconsin

October 21, 1975

Regarding your letter of October 17, 1975, I am happy to submit the following information for your examination and use.

My arthritis probably started many years ago, but the acute stage began several years ago with a flare-up which put me in bed and then in the hospital, while I was on an assignment in Rhinelander, Wisconsin. The doctor who treated me used several drugs plus complete bed rest, and I was released in a much improved condition after several days. However, from that time till now, arthritis has been my constant companion in many manifestations of pain or discomfort and even emotional problems experienced during the adjustment to this disease.

After my stay in Rhinelander, however, I was fortunate to have been directed to Marshfield Clinic and subsequently to Dr. Grace in Green Bay. They both diagnosed the problem as rheumatoid arthritis and began treating me with a regimen of aspirin and Indocin, which, after 14 months of use, allowed me to return to a limited work schedule and activities that had been dropped previously.

During the time of treatment, I think it important to observe that the Indocin was dropped and that I just could not have done without the two to three hot, hot showers that I took daily. Also, another point that I think important is that, now that improvement is realized, moderation in all phases will pay untold dividends. Just as soon as I overdo, I pay the cost in pain and a mandatory rest period.

In summarizing the first page of my letter, what I think I would like to make clear is, that even in the case of a very severe evidence of arthritis, an early, corrective diagnosis, plus the prescription of the right drugs or medicine and the faithful use of them by the patient, can and will result in either a cure or an improvement that will return the patient to a useful and happy life.



My personal opinion on the unmet needs relating to this disease would be further research into the cause, so that while we effect cure, we are also stopping it at its source. I think that my next priority would be in the direct interest of the afflicted arthritic, in the provision of a semilocal clinic, where if nothing else, he could find expert or trained personnel who could advise (if not treat) the correct type of methods to alleviate pain through the use of exercise, heat, and manipulation, etc.

I realize that we cannot have a Milwaukee or a Marshfield in every town in the State of Wisconsin as a complete clinic site, but I do think there should be an office in each region of the State that deals specifically in the problems of arthritis. At the present time, the Yellow Pages in the phone book will list practically every known specialist there is for all illnesses ranging from pregnancies to proctoscopic, but not one is listed as a specialist in arthritis, and "A" is still the first letter in the alphabet. Right now, today, I would not know which doctor to contact in Green Bay who had had special training in the disease of arthritis, except that I was advised by the Foundation in Milwaukee.

While I don't think that I can make the meeting in Milwaukee, I do thank you for the opportunity to participate by letter and I hope my comments will be helpful.

MRS. KENNETH ISAKSON  
Eau Claire, Wisconsin

I am a 31-year old arthritic patient. My wish is for a relief for pain in my condition. Also of disability of mine, there should be a Social Security payment for medical payment. Next I would like to see more research on arthritis.

Sorry I am not able to be to the meeting due to health, but would like information on it.

MARGARET JAGGER  
Milwaukee, Wisconsin

October 17, 1975

It would please me very much if more was done in the area of research for the arthritic. Much has been done for all the other organizations, why not a telethon for the Arthritis Foundation? I am 60 years old and have had arthritis for 23 years. I am in pain 24 hours a day, and I really hurt. I take 8 to 10 aspirins a day to keep it under control.

My sincere thanks to you for letting me sound off.

Milwaukee, Wisconsin

November 10, 1975

HAZEL KEVILL  
Oshkosh, Wisconsin

October 23, 1975

I have arthritis in all my joints, starting in the 1940's. It is gradually spreading and getting worse. I do most of my own work. I am not crippled, but can walk only a short distance with the use of a cane, and sometimes I cannot write a legible letter. I used to be a very good penman.

From time to time I have very painful flare-ups. I spend most of my time in a chair with a cushion at my back, or on my couch with my aching back against the firm back of the couch. I think the most urgent need is for medical scientists to find the cause of the disease. Without the cause, how can one find the cure!

MRS. DONALD F. KLAPSTEIN  
Milwaukee, Wisconsin

October 27, 1975

I found the course offered at St. Luke's Hospital about two years ago--on how to cope with physical difficulties when you have arthritis--most helpful.

Education on how to help yourself and to make your daily tasks easier is very important; and to continue this--as you forget--and it could be refreshed.

Until I attended this clinic, no one had stressed how important it was to rest--and proper exercise! It was until then, the most useful information I had received since I had been informed I had it.

Also, it is most irritating to hear the aspirin commercials comment, "To relieve the minor aches of arthritis." There is nothing minor about it; it is depressing having it described thus.

More and more research--so that if we cannot be cured, perhaps our children will be spared.

MRS. L. C. LAATSCH  
Milwaukee, Wisconsin

October 28, 1975

I am very much concerned about the slow pace of development of corrective medicine in the field of arthritis. I feel that research should be accelerated, especially in the osteoarthritis field.

Having had osteoarthritis for 15 years, I know the constant pain involved. Aspirins help somewhat, and it seems that is what most doctors prescribe, and sometimes Indocin or Darvon. However, what is needed is more help for all who have this terrible affliction.

I definitely feel that there has not been one new development in the osteoarthritis field in the 15 years that I have had it. I was told then to take aspirins, and that is still the same answer all doctors give.

It's about time something is done to help ALL who have this miserable disease.

AUGUST J. LINDER

October 21, 1975

I have been suffering from arthritis for about 15 years now. At times this is VERY painful and it seems never to get any better but worse all the time. Travels from the hands to the legs and feet. At times I can hardly write because of swollen fingers. Other times it is the legs and ankles that are painful to the extent that I can hardly walk. I can never go to any place where some walking is required, so am limited to the places where I can go.

It seems that in this day we should be able to research this crippling disease so that many of the sufferers can get some relief without going to some high-priced surgeon. It should be that the common people can get relief with getting help from a plain general practitioner.

In connection with this I would say that the medical profession should work together with the researchers so that they could come up with some care and treatment in the early stages of this disease. Besides aspirin, my doctor has put me on various helps in the drug line as they came along such as Indocin and now the new pill Motrin. BUT these do NOT help very much over aspirin, if any help at all. The medics just do not know what to do if aspirin cannot solve the problem.

And too much of this is not so good either. But these are things, or rather drugs that the average person can buy, yet, nowadays. I am talking about the average wage earner who has limited income. In my case I could go further but can find no one who can do anything about this disease. I have tried baths at Hot Springs and also the massage board in hot water at home. Seems to relieve a little but there are no cure.

I think that in the meeting there should be a mixture of the medical professions, people with arthritis, industry representatives, and the community service and funding agencies. Several of our friends are at this time in wheelchairs as nothing could be done about this disease.

The above are my comments on this meeting. I am happy to say that I am still mobile and able to get about and drive my car.

ADELINE LOHR

October 25, 1975

My most urgent unmet need as an arthritis victim is a cure, or at least a means, to arrest the steady advance of the disease.

My doctor is managing my case, and I've been on drugs now since April 1972.

The pain and limitations hourly dictate my actions in the kindergarten classroom where I am assigned by my employer, the Milwaukee Public School



November 10, 1975

System. After a summer's rest I realize each fall that it takes its toll, and I'm more limited than the previous school year.

In addition, my 84-year-old mother lives with me. She has been in a wheelchair now for 10 years--a victim of osteoarthritis.

L. F. MADLAND, R.Ph.  
Milwaukee, Wisconsin

October 20, 1975

Arthritis is a frightening disease. It creeps up on the unsuspecting like a thief in the night. People afflicted with arthritis suffer great pain and discomfort and with very little understanding by the public. The pain and crippling is often worse than cancer because the afflicted may live a long time.

Improving health delivery services to the arthritic is not enough. More effort should be spent on the cause and prevention of this terrible disease.

MARCELLA MASHUDA  
Brandon, Wisconsin

October 30, 1975

As a member of the Arthritis Foundation of Wisconsin and also one of the many, many sufferers of rheumatoid arthritis, I am submitting the following statement.

When I was informed, by my doctor, two years ago that I had rheumatoid arthritis, I felt like my world had come to an end and there was no hope. Fortunately I have experienced remission until recently, and I am able to hold down a full-time secretarial position; but I have also experienced the great pain of the disease.

My only hope, and I'm sure that of others like me, is that a cure or help will be found through intensive research in the near future. I am grateful for the support and the great work the Foundation is doing to combat the crippling effects of arthritis.

Regret that I will be unable to attend the hearing because of my employment.

MRS. IRMA MATTUSCHEK  
Milwaukee, Wisconsin

October 21, 1975

As an arthritis sufferer for 15 years, I wish to make a few comments.

I would like more Research on arthritis.

Also, I would like to see more reasonable fees for treatment, diagnosis, and care of arthritic patients.

Milwaukee, Wisconsin

November 10, 1975

The "Self-Help Program" is very helpful. I attended the meetings, and they were beneficial to my rheumatoid arthritis condition.

MRS. ELSIE MEIDER  
Sussex, Wisconsin

October 25, 1975

It is gratifying to know that there is concern being generated for the arthritics of Wisconsin by the coming of the National Arthritis Commission to Milwaukee.

My most urgent unmet need as a person who has arthritis is the fact that my doctor, as many other doctors, can prescribe very little relief for the ever present pain in my joints.

To describe what it is like to have arthritis is to say, once you become afflicted you are miserable a big share of the time. To perform as a working human being is most unpredictable. One just longs for relief from pain.

The unmet needs in my opinion are: research, treatment, and information as to a cure.

How are these needs to be met? In these times of inflation, tight budgets, etc., one would expect the Congress to help appropriate funds, private sectors, and individuals interested in the cause. I believe there should be established channels of communication who would exchange the newest developments and progress in the treatment of arthritis, involving all doctors and researchers over the U.S.

Those, in my opinion, who should articulate the needs of the arthritic are: medical professionals, allied health professionals, people with arthritis, and community service agencies.

WALTER R. MEIER  
Milwaukee, Wisconsin

October 21, 1975

I personally feel that research and development should be the prime considerations of the National Arthritis Commission.

A member of my family suffered with arthritis for 25 years, became a hopeless cripple, and the disease ultimately caused her death. Over the years many fine professional people did all they could for her but they just didn't know enough about the disease.

Knowledge is needed and that's why I believe priority should be given to research and development.

Milwaukee, Wisconsin

November 10, 1975

H. CAROL MURPHY

October 29, 1975

As a person interested in pursuing a health profession, and one with mild arthritis symptoms, I have many thoughts on the subject. In this letter, "arthritis" is taken to mean rheumatoid arthritis.

I would like to know more about what research is being carried out, in what areas, and from what perspectives. What is being done to investigate the effects of stress, unexpressed anger and frustration, movement repression, and other psychological or physiological factors on arthritics?

Has there been, or is there now, any work being done on the nutritional aspects of managing the disease? What kinds of drugs might be used to relieve the pain and stiffness besides aspirin and other toxic drugs with unpleasant or dangerous side effects? Has anyone looked at marijuana as an analgesic, antiinflammatory agent? (From personal experience, it works better than aspirin.) What kinds of events have been identified as triggering the onset of the disease, or subsequent attacks?

As a patient, I have felt that my doctor, a specialist in rheumatic diseases, was not being open with me and was not giving me enough detailed information to intelligently and effectively deal with the problem, even though I was asking for this kind of information. What I did get came out as medical platitudes.

I think patients should be as fully informed as possible, in as much detail as possible, and should participate in the decisions made as to management, course of treatment, test results, etc. One has enough anxiety over being arthritic without adding more. This kind of approach could go a long way towards eliminating some of the quackery people fall for.

Regarding the possible effects of stress, repressed anger or movement, etc., it would be useful if there were places people could go to begin breaking out of those moods. Sports and heavy exercise are much too violent, and swimming is not available or possible for many people. Things like creative movement, some forms of dance, eurythmics, bioenergetics, etc., should be explored as possible ways to keep the body moving in positive, constructive, therapeutic ways.

Finally, persons with arthritis of all kinds should be encouraged to keep daily accurate records of things such as food, sleep, stresses or emotional upsets, medication, weather, activities, pain and/or stiffness levels, and so on. Then the physician should help the patient begin to see any correlations which exist, if any, as an aid to management. For example, asparagus and brussel sprouts make my knees hurt.

I hope this will be of some help, and I look forward to being at the meeting on November 10.



Milwaukee, Wisconsin

November 10, 1975

GEORGE M. NECKERMAN  
Madison, Wisconsin

October 20, 1975

I have ankylosing spondylitis and am confined to bed not less than 18 hours a day. When I am out of bed I wear a Florida type brace.

My need--and I know it cannot be met--is to find some medication which will improve my condition so I can either go back to my office job or be up as much as 12 hours a day. I am 62 years old and would like to continue my insurance business until I am 70.

I believe money is needed to further study the causes of arthritis and medication which will enable victims to continue or resume working without suffering major side effects.

FLORENCE NETZEL  
Stevens Point, Wisconsin

October 23, 1975

Having had to live with R. Arthritis for the past 20 years, since age 38, my feelings on what should be done is that after a person has been told what the future holds for him he should have doctors who know how to treat it. Unless you go to Madison General Hospital, and I have been there, the doctors just don't specialize in the disease. If I would have had the right treatment from the onset I would not be in the crippled state I am today. Even at Mayo Clinic I was told I had arthritis, and I had to learn to live with it on the very onset of the disease.

If as much funds were available as there are to treat the alcoholics, I'm sure more young medical students would be interested. If its a matter of money, why are not alcohol and cigarettes taxed heavily to pay for all the ills they cause?

The person with arthritis cannot stop or prevent his illness like the alcoholic can. Everything has to be done for me, yet my husband cannot take an extra exemption on his tax return like he could if I were blind. Yet I have had surgery--nine operations in all and have to be waited on hand and foot.

We should have clinics for crippled so we won't have to wait in a doctor's office. But the most important is all research should be in the direction of discovering why people get arthritis, and an early way of treating it before it gets to the crippling stage.

If I can be of any help in research I would gladly give any information I can.

MRS. BEULAH OLTARZEWSKI  
Oak Creek, Wisconsin

October 30, 1975

My most urgent need as a person with rheumatoid arthritis is to find the cause and the cure of this disease. More money should be spent towards research.

I have tried all medicines, including Motrin and Cuprimine, to many side effects. My doctor, who is a specialist in rheumatic diseases, has been unable to help me. I even had 4 treatments of acupuncture for the chronic pain. I have had surgery on both hands and feet. It is a terrible thing to be so miserable all the time. I keep hoping and praying that soon there will be a cure. I have had rheumatoid arthritis for 27 years and the past 7 years constant pain.

KAREN PAAR  
Black River Falls, Wisconsin

October 29, 1975

In respect to the letter written October 17, 1975, I have been asked to write this letter. As an Arthritic now for five years I am glad to have this opportunity to explain how I feel. My whole way of life has changed considerably in five years, as I had a Beauty Salon in my basement, but when found I could no longer do my customers a favor by doing their hair, I sold my shop. My husband is an Insurance Agent, so he got me in the business also. So today I walk on carpet and do a lot more sitting, so manage really quite well.

I was 34 years old when I acquired the disease, and by that time of your life you have experienced pain and are aware of what it is. That part of the Arthritis I have learned to accept, as I thank God it is me and not my girls or my husband. But the part of it I have not learned to accept is the frustration and uneasy, disheartening moment when you reach for the coffee pot to serve your husband in the mornings and have it crash to the floor because you don't have the strength in your hands to hold it; or when the simple task of opening a clothespin is a near impossibility; when some mornings you wake up and find your feet and legs so stiff and sore they will not hold your own weight and your husband carries you to the bathroom; or having to have some one give you a hand to get out of the bathtub. I am not even too humble to ask my daughters to help me with my girdle. I used to be. When the doctor told me I had rheumatoid arthritis I thought, okay, so I've got arthritis--my husband has diabetes--everyone has something they have to learn to live with. Well the doctor explained to me what arthritis was, but he did not explain to me that the everyday simple tasks that you take so for granted were no longer simple tasks. I hope this does not sound like I am complaining, as I am not looking for self pity. I am more fortunate than many. I made up my mind it would not change my lifestyle any more than it really had to. I still ride horseback (providing someone is there to help me in the saddle); I still snowmobile short distances; and I even dance when I can. I find bowling and golf very hard to master any more, but I guess my life can go on without that.

But I would like to believe research will find a cure, perhaps even in my time. But until then there could be more training and information on teaching the arthritic that it is not the end of the world but a whole new one. Perhaps even working with an arthritic's family so they are aware of some of the emotional changes that go with arthritis. I was lucky on that account too, as my family accepted it before I did. Learning to live with pain, stiffness, aspirins, Motrin, therapy or whatever steps are necessary to take is one thing, but learning to live with ones' self is another whole new chapter.

In this day of sending men to the moon and making babies out of test tubes, let us hope that somewhere there is a cure for arthritis.

MRS. ESTHER K. PATZER  
Milwaukee, Wisconsin

October 27, 1975

NAME: Mrs. Esther K. Patzer, 75 years. DOCTORS: Mark Cicantelli beg. 9/1/74, Wm. L. Treacy, beg. 8/22/75 DIAGNOSED: By both Doctors with many tests as Rheumatoid Arthritis. Medication Pres.: Indocen, Motrin and Orazone--taken about six weeks each. Not much relief from pain. Orazone grew black hair on my face. Now taking Ascriptin, Lasix and Digoxin, with pain pill every four hours if necessary. Plenty of rest, with nap every PM of about 1-1/2 hours. Warm tub every night with a little exercising in tub of hands and feet.

I feel that nothing I have done so far has helped me a great deal, although if I don't take the medication, get plenty of rest with a tub every night, I am too tired to even stay awake. It is an effort to do anything, very difficult to be moving about for more than an hour.

I have read the book entitled There's Help for Arthritis by LaRue Stone and Lawrence E. Lamb, MD--have still to discover that help.

I do feel there should be more research made in this field for a cause and a cure, then we would not need care and community service agencies and could help ourselves. I have attended the Arthritis Foundation meetings here in Milwaukee and have seen how very many people are afflicted with this crippling disease. Tuberculosis seems to have been cured--why not arthritis? Still seems to be in such a trial and error stage.

My husband has osteoarthritis of the hip, and will have to have that drastic surgery on the hip bone very shortly, but the doctor assures him, it has been very successful in most cases.

Thank you for whatever help the Commission can come up with.



Milwaukee, Wisconsin

November 10, 1975

EDWARD E. POS  
Antigo, Wisconsin

October 23, 1975

I have had rheumatoid arthritis for 15 years. I have tried all the conventional pallatives except cortisone, which I have been warned against. At present I take two Butazolidin tablets a day, which gives me some relief. I manage to keep moving, as I know the effects if I do not. I did that once and finally had to take therapy to get mobile again.

I think the Government should have a larger research program,, as the drug companies don't wish to find a cure as it would ruin the market for their steroids and cortisone, which are expensive. An example of this is D.S.MO. It was hailed as a wonder cure for arthritis and other collagen diseases, as it could put the antismelling agent directly through the skin to the afflicted part. That was about 10 years ago,, but nothing has been heard of it since. It has been alleged that it was too cheap (a pulp wood by-product) so private initiative did not pursue it any further. This is the main reason the Government should do more research.

EMIL A. PUZA  
Milwaukee, Wisconsin

November 11, 1975

I am one of the 460,000 Wisconsin Arthritics who are asking and pleading that more research and study be done to combat arthritis.

Although I am late in sending this letter, I wish to express my deep concern that more funding from the Government is not appropriated.

Being an arthritic for many years I have gone through lots of pain and suffering as have the arthritics. So in closing I would like to enclose a check for \$2. Please continue the study and research of arthritis.

MRS. SYLVIA RADOMSKI  
Milwaukee, Wisconsin

October 30, 1975

Having been a victim of crippling rheumatoid arthritis for the past 35 years, I have endured much pain and suffering. I believe that only through experiencing this crippling and its ensuing helplessness can an individual truly come to the realization of what arthritis is.

Yet, I know that I am not alone; nearly one-half million persons in Wisconsin alone are suffering from arthritis, an overwhelming number! But, let's think of the future. Will that number increase? It is my hope that funds might be allocated for research so that the cause of the dreaded ailment could be determined.

Does the cause stem from emotional factors, insufficient diet, weather conditions, genetic factors, or ...?

Perhaps a cure cannot be found for those now afflicted, but maybe for future generations.

Milwaukee, Wisconsin

November 10, 1975

MARY RATHER  
Waukesha, Wisconsin

October 30, 1975

As a physical therapist I have the opportunity to see a great many people suffering with the pain, deformity, and disability of arthritis. I also have a family member whose love for athletics has had to be curtailed due to this illness.

The saddest part for me is to see what little we have to offer these people in terms of present therapy, be it prevention or cure. We can only watch the progressive distortion of body (and thereby lives) and offer only a dim light of hope. It is no question to me why these people will try climatic change, metallic cures, spas, overdo vitamins, eat so-called health foods, etc., etc. They have no one to turn to for a certain cure. . . only a temporary relief of symptoms and learning to cope with physical handicaps. These people and the people who try to aid them need help through research.

JOHN AND EDITH RAUDWER  
Milwaukee, Wisconsin

October 27, 1975

We understand the Commission will hold a public hearing in Milwaukee November 10, 1975, which one of us hopes to attend in an effort to find out what is being done to help arthritics.

Although we both have some problems with arthritis, we are able to lead normal lives, but we have seen and know people that are really crippled with this disease--a disease which many people are not even aware exists.

We think it would help if more information, care, and treatment were available and research carried on to try to find the cause and relief for persons afflicted. Perhaps if the Commission saw arthritis victims they would have a better understanding of their needs; and also, the medical profession could certainly point out the problems, too.

Arthritis patients will certainly appreciate every effort that is made to help in any way with this crippling disease.

MRS. RUBER A. REITEN  
Rice Lake, Wisconsin

October 29, 1975

When I heard about the public hearing the National Arthritis Commission is holding in Milwaukee on November 10, I felt very encouraged. To me, it represents a positive step towards helping the many of us who suffer the painful, crippling effects of arthritic diseases.

For the past three years I have been the victim of rheumatoid arthritis and have experienced the pain, physical limitations, emotional stress, economic loss, the effects of constant medication, and many other adversities that accompany this ailment. I am 46 years old, married, and the mother of two children, ages 12 and 15. With help and encouragement

from my family, I maintain our home and am still able to work part time as a secretary. When the disease came on suddenly and painfully, it was quite a shock and took some time for all of us to adjust to the new life style that had to take place so soon.

Early medical diagnosis and treatment has been very beneficial to me, I feel. I am responding favorably to the basic treatment program of large, daily doses of aspirin, increased rest, and physical and occupational therapy. A bad experience with gold salts injections does not encourage me to go into other supplemental treatment programs which might produce serious and unwanted side effects. The new medication I tried late in 1974 did not provide the effective relief I received from aspirin, and it was discontinued.

While I am very grateful for doing well on existing available treatment, I cannot help wondering how long it will work for me and the many other people who are in this same condition. My daily experience with rheumatoid arthritis tells me that it is a disease of ups and downs, flare-ups and remissions, and requires that I must constantly adjust and compensate as these occur. Perhaps the greatest concern to me right now is the future. What does it hold for me and others like me, who are now able to keep the disease under control but may not always be able to do so.

My immediate concerns for the future are these:

- (1) Can we be assured that research will continue and be directed not only to better care, treatment, and diagnosis, but to the ultimate goal of finding the cause and cure of arthritic diseases?
- (2) Will it be possible to train enough personnel to work and meet the needs in the field of arthritic diseases?
- (3) Will there be increased efforts directed towards educating everyone about arthritic diseases? The media in this country could certainly make this possible--call in the experts! Public apathy must go!
- (4) Will there always be money enough to do the research, training, education, treatment, and meet all the other needs that arise in the field of arthritic diseases?

It is my hope that many people are expressing their concerns and that, from them, your efforts can be directed to recommending a plan to include a means of adequate funding and a total commitment on the part of everyone involved to set out to achieve the highest goals possible in the areas of research, training, development, education, better care, treatment, diagnosis, and the ultimate goal itself, a cure! I feel it must be a unified effort of all concerned individuals in the medical profession, the allied health professions, government officials, representatives of labor and industry, community service and funding agencies, and last but not least, the people who suffer from arthritis.



I have read that the total annual cost to the national economy due to arthritis (lost wages, medical care, etc.) is near \$4,000,000,000! Federal appropriations for programs to combat arthritis, I feel, would economically be a good investment for the taxpayer. It would seem that such funding would eventually pay for itself and reap dividends if arthritics can be rehabilitated to the point where they are able to work or function normally again, pay their share of taxes, and are no longer dependent on Governmentally funded agencies for medical and other financial assistance.

If we are to have a spokesman, I would recommend that it be a doctor who specializes in arthritic diseases--someone who is very articulate and experienced in his field. If possible, I would also recommend that an individual with arthritis be utilized as a spokesman--someone who is equally articulate. How many of us have met at least one arthritic who is hopelessly crippled, but still possesses a clear and rational mind.

My family and I are very interested in the outcome of the November 10 hearing and would appreciate receiving a response concerning it. I hope my letter will be of help in your efforts as Chairman of the National Arthritis Commission. It has been a privilege for me to share my thoughts and feelings.

MRS. EARL ROSENKE  
Racine, Wisconsin

October 27, 1975

I've had arthritis for eight years. I do have medication to make me fairly comfortable. The unfortunate part, though, is noticing each year the disease is a little more advanced and is making a steady crippling effect on my joints. Although I have medication for pain, there is nothing available to retard this disease, only to relieve it. I think there is a real need for research into at least slowing the progress of arthritis.

MRS. GORDON RUEKIN  
Black River Falls, Wisconsin

October 27, 1975

More Government doles (and controls) are scarcely a popular subject these days. I am so thankful that this Commission is headed by a doctor instead of some professional "bureaucrat." I have faith in your interest and sincerity--and ability.

I believe that research should have the first and foremost consideration of the Commission, with the objective a positive cure and preventative.

Next, I'd urge immediate care for seriously affected children through grants or aids (if necessary) without excessive confusion and red tape. Children should have priority with our overworked specialists, but surely we need more doctors specializing, also.

This is a depressing and frustrating ailment even without the excruciating pain that some have. All the happy chores of housekeeping are now so time-consuming and tiring. I hate to be a complainer, yet resent giving the impression of laziness. Therefore I do appreciate the articles and news items that explain our predicament to the public. We also welcome stories of successful surgery and (hopeful) new medicines.

I have no special "unmet needs" at this time. Some days are good and some a bit miserable. I am most fortunate in seeing, regularly, a doctor who is both interested and well-informed; a cheerful person who doesn't reveal any impatience.

We live in a progressive community with plenty of services available--such as hot meals delivered to shut-ins by volunteers, etc. (I do not need this.)

I believe the medical profession and arthritics, themselves, should be heard first by the Commission. However, so many of the latter group would be unable to attend hearings or even have the courage to expose their awkwardness before this group of important persons.

Also, we have known of hearings which were monopolized by groups with selfish, personal interests. Some Government agencies "work" very hard at promoting a demand for their "services." At the local level, we observe this.

Elected officials and representatives of industry and labor can, perhaps, supply some statistics but may know too little, personally, about this disease.

Please don't classify us as a public problem or nuisance to be lumped and lost in the social services bureaucracy where administration costs leave little for the objects of their concern.

MRS. GORDON RUDKIN  
Black River Falls, Wisconsin

October 26, 1975

Recently I received your news of a coming "hearing" with a request for opinions.

This is a peculiar and puzzling ailment (RA) and seems to follow no particular pattern or schedule (for me), so you may gather some varied and conflicting suggestions.

- (1) I'd like to see the bulk of funds used for research. Also, since doctors can't take time to listen to every single symptom, emotion, or notion, perhaps these could be sent to some center searching for clues. Somewhere there must be an answer; a common denominator.
- (2) Urge every arthritic to subscribe to membership in the A.F. Provide a blank in your publication for submitting the names of

known sufferers. Spread encouraging news. For me, good news is the best medicine, just as the opposite is true.

Since getting cut to meetings, etc., requires so much strength and effort, written material is most welcome.

- (3) Urge doctors to refer patients to an interested doctor, if they lack the patience to deal with long-term illness themselves.
- (4) Give publicity and deserved recognition to area doctors who demonstrate a progressive attitude. [How much we appreciate Dr. George Liang (La Crosse). He may feel impatient or even amused with me but never shows it.]
- (5) Please deliver us from being lumped and lost in the Social Services bureaucracy. I realize the big money in this department is a temptation, but the services imposed are another matter.

Social workers, supposedly, are educated to serve the confused, delinquent, needy, addicted, alcoholic, venereal cases, etc. They are so obsessed with "problems" that they can promote worries where none exist. (Note their "sex study" in a previous bulletin.) I'm convinced that some Government agencies exert their greatest effort in promoting a demand or need for more services, and a few of these professionals are capable of confusing even a health person. (A personal prejudice.) One social "worker" admitted that "they have oversold themselves in the services they would provide." (Perhaps I'll eventually be needy enough to nullify this last opinion.)

Farm wife--age 61. Husband living and well. Three children.

MRS. FRANK D.- RUFFALO  
Racine, Wisconsin

October 23, 1975

I am concerned about the Arthritis program in our country. As many know, the doctors do not know enough about this illness to do anything about it. Fortunately for me, I do have a doctor that cares.

I have had a mild form of arthritis for a long time. Three times I have had flare-ups that have disabled me for short periods of time (months). Fortunately for me, these flare ups have gone away and I am just left with the regular stiff jointed, hard to get up in the morning, type of thing.

I feel that we should have a good research program going and have a good education program for all people who should be concerned -- doctors, nurses, patients. Until this is done it is a little hard to train people other than to live with what they have.



Milwaukee, Wisconsin

November 10, 1975

AUDREY SCHMIT  
Port Washington, Wisconsin

October 1975

As an arthritic for 8 of my 45 years, I would like to see more research to find the cause and cure of this disabling condition.

For a disease that can strike any age or sex, with varying degrees of severity, for the rest of their lives, it behooves us to set our sights on it with more research and stop it. It takes money.

Most of us would rather be in the job market than rehabilitation centers, even though they are needed, too.

MRS. WALTER O. SCHWARTZ  
Milwaukee, Wisconsin

October 30, 1975

If you should have all these additional funds, I do believe research and really try all fields--allergy foods, digestive track, water therapy, educate the public--young also have rheumatoid disease.

I am for better care and treatment. At times I don't believe it is treated seriously, and it is misunderstood.

Yes, I believe you should have several arthritic men and women on your boards. Since it affects more women, why not take advantage of their knowledge with continuous pains.

Everyone should be involved with this ANCIENT disease. Your list is complete. May you have a successful day, November 10. If I'm not too stiff, I'll be there.

UNMET NEEDS:

- (1) AGAINST heavy heavy doors to enter and exit buildings.
- (2) Buses: Greyhound high steps.
- (3) City buses also are too high. HAVE Door handles inside of bus on both sides, now only one side; right side getting on bus--one must reach over to the left for only handle trying to get out of bus quickly.
- (4) AGAINST heated buildings with the lukewarm steady blowing air. (Chilling effect)
- (5) Push-in spray cans--impossible for me--household waxes, bathroom deoderants Cottage cheese containers (tops) hard to remove.
- (6) FOR Reasonable priced bathtub equipment to get in and out of tub.
- (7) Plus a few personal things.

Milwaukee, Wisconsin

November 10, 1975

MRS. DONNA SCHOTT  
Green Bay, Wisconsin

October 27, 1975

Eight years ago, at the age of 33, I developed rheumatoid arthritis. At that time I had a little girl, age one, and was unable to care for her and for myself for several months. This to me was the most painful disease I can ever imagine. So please try to understand our needs.

I understand the Commission would like input from patients with arthritis. I feel there are many needs, as up to the past few years it was then stated, "live with it."

I feel there are several needs which I hope will continue to expand.

- (1) I feel much more should be put into research so hopefully they can find the cause.
- (2) Would like to see more physicians specialize in arthritis and related diseases caused by arthritis. Also, that each area would have at least one specialist to serve the people.
- (3) Expand the self-help program to more. Get more cooperation of area physicians and hospital physical therapy departments.
- (4) See that the community services provide more care, especially to persons living alone; such as meals, basic needs.
- (5) Again, research for newer drugs, hopefully with less side effects.

I thank you for your time and hope some of these thoughts can be expanded.

JOHN W. SELZER

October 1975

I have arthritis on my knee. Sometimes the pain is unbearable. My arthritis is not as bad as some people who have it, and seeing there is no cure for it they will go through the rest of their life with it, unless there is more found out about it.

MRS. EUGENE SELL  
Elm Grove, Wisconsin

October 1975

I have two sisters and one brother whom I have observed becoming crippled from rheumatoid arthritis. They have used everything from aspirin--cortisone--to gold shots. Nothing seems to help. I have gone through pain just looking at them. Now to really kill me is to see this horrible thing happen to my youngest daughter, only 22 years old. She has been diagnosed to have the beginnings of this disease in her knee and hands. Her pain is my pain.

Milwaukee, Wisconsin

November 10, 1975

Please do more research so this disease can be stopped before it ruins her life.

VERLE H. SMITH  
Milwaukee, Wisconsin

October 22, 1975

Help! Help! Please may we have enough research to find some way so that I may have a few minutes at least now and then to be free from nagging pain. Enough money available so that the drain financially, in everyday care doesn't take all of our extra funds. An organization that will give us a reason to help but also be a morale builder for ourselves. Yours for a day without pain.

ED SPANGENBERG  
Milwaukee, Wisconsin

October 21, 1975

I understand your Commission is holding a public hearing November 10th.

I cannot attend, but I do hope that because of this hearing the existing program will be continued and more emphasis can be put on research. I am not active in the Foundation other than my financial support.

NORMA STUDE  
Milwaukee, Wisconsin

October 20, 1975

As an arthritis sufferer for over 40 years, I am sorry I will not be able to attend the public hearing on November 10th. My reason, I have other health problems at age 74, also do not travel very well.

I think the unmet needs are research, better care, treatment and diagnosis, and feel this should be brought before the Commission by medical professionals and maybe people with arthritis.

MRS. GLORIA SWENSON  
Brookfield, Wisconsin

October 28, 1975

At the age of 42, when Dr. Ziebert, my internist, discovered that I had rheumatoid arthritis, my first reaction was, "Why, that's an 'old folks' disease!" However, it did not take long before I knew the miseries of this disease, terrible tiredness, swollen inflamed joints, no strength in the hands or feet, and pain. My dismay at not being able to open a jar, a dishwasher, or the car door without experiencing great difficulty was very discouraging.

Fortunately, Dr. Ziebert and Dr. Kozin found the right combination of medications for me, aspirin, hyerychlorequine, and Gold shots, and I am



much improved and leading a normal life. This is my prayer for all arthritics.

I feel that lately the public have been much more informed as to this disease and its problems, but much more publicity should be stressed. The typical reply of people still is, "But you look so good," when you are absolutely miserable. Families of the arthritics, too, should be counseled as to the limitations and unnecessary strains that should not be imposed on the afflicted person. However, the big question still remains, "What causes arthritis?" Until an answer to this question is found, a cure seems very remote. Research must remain number one in priority, but helping the arthritic to lead as normal a life as possible with education, understanding, training, and of course correct treatment is extremely important.

Arthritis may not kill as Cancer or Heart problems do, but it can create a life of prolonged agony usually culminating with the afflicted person confined to a wheelchair or bed. Which is worse? I pray that a cure will be found soon.

MRS. D. TRYTHALL  
Elcho, Wisconsin

October 24, 1975

I believe the medical professionals should be responsible for finding a cure and treating patients for arthritis. At present there seems to be a wide difference among physicians of methods of treatment.

In our area (Langlade City, etc.) the Marshfield Clinic would be the logical recipient for funds for research.

I've been suffering terribly for three years with almost no relief, except temporary from rubs, massages, and moist heat applications.

MRS. C. VOSICKY  
Geneva, Wisconsin

October 27, 1975

I am 70 years old. I have been troubled with arthritis, rheumatoid arthritis, for the past 10 years. I have had pains in my knees, hands, arms, and at this time it is in my hips and back, which is very painful. I have had some relief from the Indocin capsules prescribed by my physician. After they stopped working, I was given gold shots--after which I developed an itching rash, so that had to be stopped. Now I am taking Aristocort four, which gives me some relief. This pain keeps me very much from doing the ordinary things I was able to do.

I would like to see more research on what is causing this disease, on foods that may be causing this, also on the development of a drug to stop the awful pains.

It would be nice to have a local agency in Walworth County to provide information on the latest development in research and to provide help for people suffering from arthritis.

I hope that the Commission's hearings will be very successful. I am enclosing a check for \$2.00 for the Arthritis Foundation of Wisconsin.

MRS. RUTH V. VOY  
Horicon, Wisconsin

October 28, 1975

What causes arthritis? What a breakthrough this would be if we could find the cause of arthritis. So, obviously we need more research done in this field.

Is there a cure for arthritis? Not yet; but what a glorious day when we find the cure for arthritis! So we need more work in this field.

Do I have arthritis? People need to be convinced of the necessity for early detection. When I was told that I had rheumatoid arthritis 28 years ago, I thought arthritis was for old people and that the doctors were wrong. It didn't take long for me to realize my mistake! So people need to be educated about the symptoms of arthritis so they can go for early detection and treatment. Then we must realize the necessity of following the doctor's orders exactly. We must learn to close our ears to all the "friendly suggestions of how to 'cure' arthritis. As of today a 'cure' is a 'quack'."

To what doctor do I go? We have a crying need for people who are really and truly informed about arthritis and who will then show some interest in the patient. There are all too many doctors who hate to see an arthritic come into their office. For 26 years I traveled a round trip distance of 165 miles every time I needed a doctor for my arthritis. Often this was every week, sometimes every two weeks, but always at least once a month. Why did I go so far? My family doctor that I had as I was growing up was the only doctor I could find who was interested enough in me and my arthritis and knew enough about arthritis to want to help me. When I went to Dr. Stuessy I knew he would try every safe thing available to keep me going. I knew he cared. We don't need sympathy, but we do need doctors who care about their patients. Since Dr. Stuessy passed away I was fortunate to find another doctor closer to home who cares.

What treatment is available? There has been a great improvement in treatment over the years. But I'm certain that we need more research and help in this field. People need to realize the importance of following doctor's orders. The correct amount of rest and activity has to be worked out so that the body gets enough exercise and also enough rest. Range of motion exercises done every day, not just when you feel like maybe you ought to do them, are so important in keeping the joints moving. The lowly little aspirin is the mighty big aspirin in the treatment of arthritis.

It is to be taken as ordered by the doctor, not just when you think you need it. There are other medicines too that help to keep us going. Maybe some day someone will find a medicine that will stop arthritis. Then there is surgery for arthritis! This field has made wonderful progress in helping the arthritic. How well I know! Besides other surgery I have both total hip replacements and both total knee

replacements. I have had a tremendous relief from the amount of pain that I had before. This relief alone is wonderful, but now I can move much more freely. After nine years in a wheelchair I can now get up and walk away from it. Once again I was lucky enough to find really good surgeons who are dedicated to helping the arthritic. But it took some searching to find them. I know of people who keep searching and never seem to find the wonderful help that I've had over the years.

Yes, we need dedicated people to treat the arthritic. These people have to be trained. We need more research in the field of arthritis. I'm waiting for the day when arthritis can be stamped out like polio. In the meantime we need more arthritis treatment centers. People need to be taught the importance of early diagnosis and treatment and the importance of following the doctor's orders. With early diagnosis and proper treatment that is available today many people may be spared a lot of the agony that we suffered in the days when not much was known about arthritis.

Yes, as an arthritic I see a crying need for help for the arthritic and for those who will be developing arthritis if we don't find the cause and cure for arthritis. No one can see the pain that an arthritic is suffering. No one sees an arthritic at his worst because he stays home then to try to become more comfortable. So just because our agonies are not seen by others is no reason to delay research and treatment developments.

KATHLEEN S. WEICH  
West Allis, Wisconsin

October 21, 1975

My rheumatoid arthritis started on March 16, 1966, and I have not had a day without pain since.

It started in my right knee, then went to every joint and muscle in my body. Since the middle of August 1968 I have been unable to work. Gradually my fingers drifted outward, and my hands became cup-shaped. I don't have enough strength in my hands to change the channel on my TV, turn a key in a door, or put a plug into a socket.

This is a terribly painful and very depressing disease. One is reduced to almost total dependency on others at an early age, with no hope for the future.

I don't feel that sufficient research is being done to find the cause, as well as the cure, of this dreadful illness.



Milwaukee, Wisconsin

November 10, 1975

K. S. WELCH  
West Allis, Wisconsin

October 1975

I'm sitting in my wheelchair, crippled up with rheumatoid arthritis. I have the National Observer, a newspaper, spread out on a table in front of me. Painfully I turn the pages to read the current events and I find this ridiculous article, "The fish are suffering from the polluted waters, let's get the waters cleared."

This appropriation could be used for something beneficial to humanity. I'm one who is interested in rheumatoid arthritis research. We not only have the physical pain, but the pain of depending on others.

ARTHUR G. WICK  
Milwaukee, Wisconsin

October 28, 1975

Research to discover the primary cause of all forms of arthritis and rheumatism is a necessary must.

To discover how to arrest and treat these diseases once they become apparent. To discover how to restore, as far as possible, bodily functions as they were as normal, healthy conditions prior to the onset of arthritis and rheumatism.

A Federal permanent fund is needed for the purpose of paying medical and hospital fees or expenses to those with the above diseases to enable those unable financially to restore themselves to taxpayers and self-supporting citizens, rather than to continue to allow these people to be economic liabilities to the nation.

Any disease with (as you say) 460,000 men, women, and children as permanent victims is a disease of such magnitude and must have a solution.

ROBERT C. ZUEGE  
Milwaukee, Wisconsin

October 30, 1975

As a physician I am associated with the multi-disciplined approach to rheumatoid arthritis at Columbia Hospital, Milwaukee, Wisconsin. This is in conjunction with rheumatologists, physiatrists, and paramedical personnel.

It is my feeling that the National Arthritis Act of 1974 should be implemented to improve its force in research and continuing education.

There is also a need for a convalescent care unit for arthritics following surgery and for those who are unable to care for themselves at home. This would cut the cost of expensive care in an acute medical facility.

JUANITA S. ABRAMS  
Wausau, Wisconsin

October 27, 1975

Being an arthritic for many years, I feel justified because I cannot live alone and cannot write. I have had both knees replaced. Arthritis changes your whole life.

What is needed most is training of more doctors who understand the needs of arthritics, and also research.

The ones who should articulate before the Commission should be medical professionals and people with arthritis.

WILLIAM R. AUSTAD, M.D.  
Monroe, Wisconsin

October 23, 1975

I am a practicing rheumatologist, member of the Department of Internal Medicine of The Monroe Clinic, Monroe, Wisconsin.

The following are my feelings and suggestions as to the problems of arthritis in the State of Wisconsin and what can be done to improve these difficulties. I feel that the education of the medical students, interns, and residents at the University of Wisconsin is markedly lacking in the field of rheumatology. We have fourth year medical students rotating through our Clinic as preceptees, and their grasp and insight into the problems of rheumatology are very minimal. We have the University of Wisconsin Medical School resident (both Family Practice and Internal Medicine) that work in our Emergency Room at St. Clare Hospital on weekends, and their grasp of rheumatology and rheumatologic problems is minimal. I feel that the physician education has to begin at the grass roots in the medical students, interns, and residents at the University and feel that this is a much more logical and effective means of education than attempting to educate physicians in practice. The availability of review material, self-education material, etc., to the practicing physician in the field of rheumatology from the drug companies in general is not available to the medical students, interns, and residents.

I feel that encouragement of a strong Department of Rheumatology at the Universities with the establishment of an active Rheumatology Fellowship Program needs to be encouraged, and also that the fellowships should not be only in research. I feel that the fellowships have to include and be part of the student, intern, and residents education so as to mold physician training early. I think research, as such, is necessary and I have the feeling that there is much duplication of medical research in the field of Rheumatology, and I think that research into the ability to educate needs also to be explored, along with the research into the basic causes of the arthritic problems.

Milwaukee, Wisconsin

November 10, 1975

JUDITH C. BAUTCH  
Madison, Wisconsin

October 29, 1975

Quality arthritis care for a greater number of citizens should be an overall goal for all of us associated with the Foundation. Education and training of new health care workers and the establishment of new programs is both costly and time consuming. However, I do not feel this approach should be abandoned. It is my opinion that the greatest amount could be accomplished by education of those individuals already in professions and clinical settings.

This will mean better in-service education, continuing education programs, most basically better provision of information and training experiences in professional education programs.

In the area of research I would favor variable amounts of funds being available. This would encourage professionals to do research, but it would not obligate them to a full-time research commitment.

I regret I am unable to be at the hearings on November 10.

JAMES F. CAPE  
Racine, Wisconsin

October 20, 1975

I am pleased to have the opportunity to express my views, as it relates to the needs of arthritics. Obviously, the most important one is the conquering of the disease. But, obviously, a program to more effectively enlighten doctors, nurses, and the personnel who work with arthritics is a most necessary factor to help alleviate the discomfort and the problems of the patient.

Over and above the medical treatment, there is a great need for supplementary attention to support material for the more severe arthritics, such as elbow cushions and items to make them more comfortable when the disease reaches a stage where continued bed rest is imperative.

Helpful hints for the families of arthritics and how to cope with the discomforts of the patients and give moral as well as physical support is also a definite need and help.

BURTON J. GROSSMAN, M.D.  
Chicago, Illinois

November 3, 1975

I am writing you regarding my appraisal of the needs for facilities for pediatric rheumatology in the Chicago Metropolitan area. This is being done so that I can have some input into the investigations of the National Arthritis Commission.

The Chicago Metropolitan area encompasses the entire area of northwestern Indiana and northeastern Illinois along the shore of Lake Michigan and inland approximately 50 to 75 miles. Chicago is the medical center of this area serving over 25,000,000 people. In the entire Chicago



Metropolitan area there are only two centers devoting themselves to pediatric rheumatology: (1) the Immunology Service at Children's Memorial Hospital (Northwestern Medical School), under the direction of Dr. Lauren Pachman, and (2) the Pediatric Rheumatology Service at La Rabida Children's Hospital and Research Center, a part of the Department of Pediatrics of the University of Chicago Pritzker School of Medicine, under my direction.

At LaRabida we have seen, over the 20 years of its existence, approximately 1,000 patients with juvenile rheumatoid arthritis and are currently following approximately 500 patients. We have eight half-day clinics a week devoted to pediatric rheumatology. The service has two attending physicians and one fellow in pediatric rheumatology and that fellowship is entirely supported by the institution.

Research funds, especially for clinical research, are very meager in this area. The local chapter of the Arthritis Foundation cannot raise enough money to support all the worthy research proposals in rheumatology which are currently sent to them.

There is a need in the Chicago Metropolitan area for expansion of facilities in pediatric rheumatology; need for more research, money, and money for clinical and research fellowships in this neglected field; need for expanded facilities especially for rehabilitation of children; need for salary support for physical therapists specializing in pediatric rheumatological problems; and need for support for training programs for pediatric physical therapy.

There is a need for a national center where the experience of rheumatologists dealing with adult patients and rheumatologists dealing with pediatric patients can come together, pool their knowledge and experience, both clinical and research, to try to develop better ways of dealing with the general problems of arthritis.

The number of children afflicted with juvenile rheumatoid arthritis seems to be increasing and the knowledge and experience in this, albeit a small area, is not getting to all those who need the service.

In projecting the need for arthritis programs in this area, I hope the needs of children will also be considered.

ANN HARTMAN  
Merrill, Wisconsin

October 28, 1975

In the outlying districts where there is no rheumatologist or even medical professionals specializing in orthopedics to stress care, treatment, and diagnosis, the general public is actually uninformed except for what is read or discussed in such publications as Reader's Digest or other periodicals.

Local physicians are already overburdened with patient care, without assuming teaching responsibilities. Paramedicals could assist in

promoting information, but it would seem some of the first factual information should be presented by medical professionals.

County nursing service has many contacts with the groups in which arthritis is or could be playing a dominant role and could dispense information and suggestions as supplied by the Arthritis Foundation. Possibly some of the civic groups would be interested in becoming involved in such a project.

JEAN M. KIERNAT, OTR  
Madison, Wisconsin

November 4, 1975

Since Spring of 1972, self-help classes for persons with arthritis have been conducted in the various areas of Wisconsin under the joint sponsorship of the Wisconsin Arthritis Foundation and the University of Wisconsin-Madison Program in Occupational Therapy.

Through a series of four, free-of-charge classes, people with arthritis in a given community are informed of the basic facts about arthritis. They learn the importance of balancing rest with exercise and are taught the importance of taking their medications as prescribed. Participants learn that there is a great deal that can be done for arthritis and that they must play an active part in the management of their own programs. The concept of energy conservation, joint protection and the use of aids and appliances are discussed in relation to daily living activities! All classes have been filled to capacity and very well received.

Wherever classes are held, whether in small towns or metropolitan areas, there are always many people with very little understanding of their own disease. They may or may not be seeing a physician. Many believe that arthritis is an inevitable aspect of aging which one must grin and bear. Many myths and home remedies surface during these discussions and are replaced with more helpful and accurate information.

It has become apparent that if the health care system is to provide adequate care for persons with arthritis, an aggressive approach for identifying these people coupled with consumer-oriented education is required. To date we have relied upon volunteer efforts to provide the service described above. If we are to adequately cover the total State, funded positions are necessary for this type of community outreach.

To better serve those people who are brought into the health care system, continuing education programs concerned with the rheumatic diseases are needed by all health professionals. Physicians must be taught while in medical school to use the expertise of the allied health professionals.

Another issue which I would hope the Commission would consider is the need to aid the arthritic employee while he or she is still employed. Studies need to be conducted to identify the arthritic worker and programs must be designed in cooperation with labor and management to assist the

arthritic worker and to reduce the number of working days lost because of arthritis.

Thank you for the opportunity to present these views to the Commission. I am certain that through your efforts and the information gained from the Milwaukee hearings, the Wisconsin Arthritis Foundation will be better able to serve people with arthritis in the State of Wisconsin.

MARTHA GRAY KLEIN  
Milwaukee, Wisconsin

October 27, 1975

As one who has struggled with arthritis for 10 years, my experience with the disease and with those who have tried to help me has been quite considerable.

This statement follows in form your "Guidelines to Preparing Statements for the National Arthritis Commission Hearings."

WHAT ARE THE UNMET NEEDS? The field for improvement is so vast that one hardly knows where to begin. The lack of physicians trained to specialize in Arthritis is perhaps my most unmet need. It usually takes two months to get an appointment, and when things are really bad that is too long to suffer. Unfortunately I do not tolerate medication for pain. The number of persons suffering with Arthritis runs into approximately one half million in Wisconsin alone.

WHAT SHOULD BE DONE TO MEET THESE NEEDS? It is my firm belief that the entire field cannot be attacked at once. Perhaps three activities should have strong emphasis for the next five years, such as:

- (1) Training and research. This is a tremendous challenge. It will require wisdom and expertise.
- (2) Public Relations. This will require a first class, low key public relations person. The press, TV, and radio should be enlisted. The help of volunteers should not be overlooked.
- (3) Funding sources should be explored, viz. Foundations, Labor Unions, Industry, Brewers, and Distillers.

WHO SHOULD ARTICULATE THE ABOVE BEFORE THE COMMISSION? Each of the eight groups listed in your Guidelines should be given an opportunity to make presentations. Each group should be allotted a specific time period, and the services of a timekeeper are needed to preserve the schedule.



MRS. CLIFFORD MILLER

October 21, 1975

I think one of the greatest needs for people with arthritis is to know where to go to find a doctor who is a specialist in the arthritic field, and who can diagnose correctly what type it is and treat it accordingly.

When I first began to have symptoms 14 years ago, after the birth of our second son, I didn't know where to turn for help from someone qualified in this field. I wrote a letter to the Wisconsin Arthritis Foundation seeking a specialist, and they referred me to several internists here in Racine. The one I chose decided that being the lab tests were not positive proof of any arthritis, he told me it "was all in my head." After that the various diagnoses from four other doctors were: osteoarthritis, early rheumatoid arthritis, and arthralgia. I was almost crazy with worry over it all and felt at the time I was headed for a breakdown. The attitude of my in-laws didn't help the situation any either. My husband was not understanding of the problem which was probably the worst of all. You see, as long as you are not visibly crippled they think nothing is wrong with you.

My 22-year-old nephew had to go clear to the Mayo Clinic to be diagnosed as having rheumatoid arthritis. His family doctor, who is a general practitioner, was not qualified to treat him. He had him on gold salts right away. The Mayo Clinic doctors took him off that and prescribed aspirin.

So I feel the biggest need is qualified trained doctors in the arthritic field who can diagnose what is really wrong with you, treat it correctly, and have at their disposal channels of support and education so your own family and relations can become knowledgeable. Just as important as this need is that people know where to turn. The yellow pages should have this listed in places where anyone can search and find the help he needs at such a desperate and anxious time.

MRS. LOIS POTSCHAIDER  
Omro, Wisconsin

October 22, 1975

First of all, I first found out what I was suffering so much from was Arthritis, about five years ago. I was only 38 years old, ambitious, with 3 children to keep me busy. I was beginning to get such excruciating pain in my neck and shoulders, between my shoulder blades, and lower back. It caused me to become short of breath, headached all the time, and all my stomach and abdomen insides were constantly tender. We live out in the country and I didn't have the car, as my husband needed it for work, so I went to a nice old little gentle country doctor near my home.

After the routine tests and x-rays were taken, I was then sent for physical therapy and neck traction, with heat and deep-heat ray machine (forgot what they called it). I was also given several types of pills, and two shots in my backside, at first every other day, then once a week for a couple months, then he left it up to me, when to get the shots. After a year or so I had improved, so I could do most of my major jobs at home, but not without some pain, as I was told to understand, there is NO

permanent cure. I was also given some exercises to do, which hurt like hell at first, but don't ever think it's foolish or it doesn't help, because it sure does. After while, your hip joints and arm joints don't hurt when you use them, because you keep them liber and that helps to keep the joints from freezing so you don't get all crippled up. Oh! Yes! Tests showed arthritis of the spine--calcium deposits forming in lower back and neck.

My lovely doctor passed away, and I began to get bad again. All I wanted to do was lay down and sleep because then I didn't feel the steady aggravating, pickly, hot, tight, or knotted up feeling all the way down by spine. I tried rubs, heating pads, hot baths. My country doctor filled his own prescriptions so I never knew what I was getting. Not even the shots. He didn't like to talk either, so when I finally found a doctor who would take a new patient, I couldn't even help him out by explaining what of the drugs were already tried and I had allergic reaction to. There was no record, as he had no nurse, and he wrote down just what he needed to know and relied on his memory. The two doctors I have seen since, in two years neither can figure out what the shots were, the first didn't help my condition at all. But after a little constant persuading that there just must be something that can at least help relieve some of my pain, I was put on 15 aspirins a day (which I tolerate very well, so far), but after months noticed no change at all. I kept at it though, with this same doctor, and he knew I was at my breaking point by then, and he prescribed, besides the aspirin, a tranquilizer which I could never tolerate either, as they worked just in reverse on me; even Librium, Valium and many milder types were tried, but any liquor, beer, wine, etc, (not together of course) had this same effect on me. After all these years, I casually mentioned this to my doctor, and it seemed to make all the difference in the world, as the tranquilizer he now prescribed is Tranxene 7, 5 mg., three times a day.

I just couldn't believe it was happening to me. After just one of these I felt the terrible tension leaving my shoulders, neck, and back; within 10 minutes my headache feeling was gone. I still take 15 aspirins a day, under my doctor's supervision, and it's been 2 weeks and I still feel much better, like living again.

I still have some stiffness, a little soreness, but I've been house-cleaning, laughing and joking again, enjoying my husband and 10-year-old daughter and my 2 active grandsons once again, where I could never find the energy to do this before no matter how much I desired to do so.

Now for the part of my letter I think you most want to hear, is what I believe could be done. Through my own experiences, I really wish there were more specialists in Arthritic conditions, maybe a small clinic, close enough and enough of them so almost anybody could get to them. There are too many specialist doctors (other kinds). Our G. P.'s are much too overworked. Even if they don't mean to, we don't get enough of their time in a visit. We feel so rushed we forget half of the things we want to ask. And doctors volunteer very little information. We just cannot get a doctor, unless you already are a patient of his, and then I've found it's treated much too lightly, and brushed off with remarks like, "Well, you know, we can't treat it like a toothache." Yes, I know of all this, and I



am not a complainer, but from all your literature you send me, it says at least there is help, so I just kept at it and so far it has paid off for me. I learned a lot from your literature that our doctors don't have time to tell their patients.

I'm not much of a letter writer, but if this helps even a little bit, that's what counts.

GOD BLESS YOU ALL.

P.S. Since I had arthritis, I've noticed how many people are very ignorant as to exactly what it is. My mother-in-law told me to get some good liniment that is good for rheumatism, which to her is the same as any kind of arthritis.

HERBERT M. RUBINSTEIN, M.D.  
Chicago, Illinois

October 20, 1975

The committee of rheumatologists on whose behalf I am writing strongly endorses your efforts to formulate a comprehensive and aggressive program of improved patient care, patient and physician education, and basic and clinical research designed to improve the care of patients with arthritis both now and in the future.

The most pressing need, we believe, is for extension of existing knowledge in the care of arthritis to the hundreds of thousands, and possibly millions, of patients who now need such expert care but who, for one reason or another, do not receive it. A useful analogy is the present state of cardiology practice. Modern cardiologic diagnosis and therapy is pretty well disseminated throughout the country and the level of care is generally high. This is not the case in rheumatology. The rheumatologists of our area, and presumably this is true everywhere, are inundated by patients whose care has been substandard or who have received no care at all.

In our opinion this neglect can only be overcome by promulgating the many centers of rheumatology excellence under consideration by your committee. Such a network could provide proper care to large numbers of patients, and an important by-product of this activity would be improvement of patient knowledge about the nature and availability of adequate care for arthritis.

Along with better access to adequate care, such centers could readily undertake the kind of massive efforts at physician education that are clearly needed. If enough centers are eventually established, it should be possible to reach a very large fraction of those physicians presently assuming care of patients with arthritis with the expectation that their knowledge and performance can be significantly heightened and suitable pathways for them to refer patients to centers of excellence can be established.

Whatever the status of the number of specialists in various fields, there is a profound deficiency of trained clinical rheumatologists in our



geographic area, and I suspect this is true of the nation as a whole. What is needed is a rapid expansion of such specialists, and the establishment of the centers that you envision should make this expansion easily possible. Within 5-10 years after establishment of such centers one can envision growing numbers of rheumatologists who can begin to cope with the enormous logistic problems of rheumatologic diagnosis and patient care.

Obviously of great long-range importance is the support of both basic and clinical research in rheumatology. Basic research is needed to increase the scientific basis for newer forms of therapy, and clinical research is needed to refine and improve existing therapies, both medical, surgical, and rehabilitative.

Finally, such centers will, hopefully, serve as models of integrated medical care, with the proper balance between the efforts of rheumatologists, orthopedic surgeons, physical therapists and other members of the comprehensive health team needed to restore patients with arthritis to a life of usefulness.

HERBERT M. RUBENSTEIN, M.D.  
Maywood, Illinois

November 4, 1975

It has been suggested to me that it would be useful to document the nature of rheumatology practice at this medical school and try to predict future use. If enough rheumatologists do this, perhaps it will be useful material for analysis by your group.

At present, my colleague and I see 500-600 new patients with arthritis annually. Many of the patients are referred by other physicians but many are self-referred. Patients calling in for new appointments are often forced to wait 3-4 months, although we try to look after acute situations promptly. We are presently logging about 3500 visits to the arthritis clinic yearly.

In addition to our outpatient commitments, we have an inpatient service of about 15 patients with rheumatic illnesses.

Our institution and clinic only began 5 1/2 years ago, and the demand for our services is increasing at a very rapid pace. I believe it would be reasonable to anticipate a doubling of both outpatient and inpatient services within the next 4-5 years.

I am attempting to recruit other rheumatologists to help cope with this load, but, since it is a shortage specialty, so far without much luck. Naturally, all of us in the field hope that the planned arthritis centers will greatly increase the number of physicians who enter our field, and this may eventually allow us to cope with the tremendous task of giving appropriate rheumatologic care to the hundreds of thousands, or possibly millions, of patients who need it.

EUGENE A. RUNHOLM  
Waupun, Wisconsin

October 28, 1975

It was a year ago this fall that I found out that I had psoriatic arthritis. Two week in the hospital and four week at home accompanied by intense pain. I am now back at my job. My knee joints are damaged to the extent that eventually they may need replacement. There are so many things I have had to learn the hard way; getting enough rest, exercising, how the pain comes and goes without rhyme nor reason.

There is a real need for more research and more information about the arthritic condition. My doctors didn't offer much in the way of explanations. There is a wealth of misinformation among the lay public.

More research and more information are real needs as I see it.

MRS. E. V. RYALL  
Kenosha, Wisconsin

October 23, 1975

One unmet need that I have felt is for more know-how on arthritis in the general practitioner. My doctor informed me of new drugs, Ascriptin, when aspirin upset my stomach, and just recently, Motrin. "Nothing new" was his answer until the happy day when a new drug showed up. I do not feel he has been very helpful on arthritis.

More training on therapy and drugs for arthritis in medical schools, better training for young doctors, and ways of disseminating new knowledge among doctors would be profitable ways to attack this serious problem.

I am 82, have osteoarthritis in hips, knee, and back. I had much trouble with arthritis in my neck, but the new pill, Motrin, has improved that enormously. I cannot see that it helps the other areas especially. Good old Ascriptin is my standby.

MARY RITA STARK

November 7, 1975

I am a 27-year-old woman and I have had rheumatoid arthritis for seven years. I suppose I consider myself lucky that the disease has only delayed, but not deterred, me from completing my education; a B.A. in Journalism from Marquette University, and beginning a career in communications. It has not crippled me noticeably. In fact, people look at me funny when I tell them I have arthritis, because the effects don't show. But I know what it feels like.

I also know what it's like to live with someone who suffers a great deal from the disease. My mother has spent nearly 20 years going from doctor to doctor, experiencing discouragement and frustration. From the old country doctor in the little town where I grew up, whose attitude was, "Well, you can move can't you; so why are you complaining," to specialists who told her, "Lose 50 pounds and then come back and see me." (This, after

years of cortisone therapy. My mother does have a weight problem--when some people are anxious, they drink; mom eats.)

What would I like to see done? See more young men and women in medical school specialize in rheumatology, for one thing. Considering the long-term effects of arthritis on individuals, both physically and emotionally, as well as on their families and friends; and considering that it is the nation's number onecrippler, it seems imperative to expand and develop this field, both in terms of researchers and practicing physicians.

The next most important area seems to be information for both medical professional and layman alike. I remember being very curious when I was first hospitalized about what had caused my body to react this way--curious and frightened because I was confined to bed with a high fever, my knee was swollen to twice its normal size, and I was in intense pain. And nobody could give me a straight answer. The orthopedic man who treated me said, "Don't worry, you won't end up like your mother." A Statement which I'm sure he meant to be reassuring, but only seems slightly less bizarre now than it did then.

From being a very active young woman of 20, it seemed that I would have to psych myself up to being crippled for the rest of my life.

It also seems important to continue to keep patients informed following their initial confrontation with a rheumatic disease. Lack of information or misinformation leads to fear of the unknown and helps to make quackery the travesty that it is.

VIOLA STEVERWALD, F.N.  
Adell, Wisconsin

October 15, 1975

The greatest need, as I see it, is education of the general practitioners, so that hope can be restored in our many arthritics from all walks of life.

JACK B. TORINUS  
Appleton, Wisconsin

October 28, 1975

For a period of 15 years I experienced increasing pain and disability in both legs. A succession of physicians diagnosed my problem as "arthritis" of the knees, and their medical advice to me ran the gamut from "learn to live with it" or "you must realize you are getting older" at a period when I was 30 to 45 years of age to the prescribing of various pain-killing drugs, cortisone, Butazolidin, etc., in increasing doses.

In 1962 I finally located an orthopedic surgeon in Nashville, Tenn., who took one look at my walk and told me my problem was in my hip joints. No previous physician had even taken an x-ray of my hips, always my knees. This surgeon gave me a workable solution to my problem--weight loss, daily exercises, and the use of arm crutches.



This management program kept me going until the total hip replacement procedure became available. Today I am restored to all normal physical activity.

Not many arthritis victims are as fortunate as I. It can be truthfully said that I "stumbled upon" a physician who had a concern for arthritic patients. I received no help from any of my previous physicians in locating him. None of them made any attempt to refer me to an arthritis specialist.

This is the situation most arthritis victims face today. They go to their physician and he tells them to take aspirin and learn to live with it.

There are two arthritis clinics in Wisconsin today, but very few patients are able to avail themselves of their services. This is due to ignorance, distance, and limited resources.

Arthritics desperately need the availability of regional clinics where they may receive expert diagnosis and treatment. The training of many more physicians in the diagnosis and treatment of arthritic ailments is a necessary prelude to the establishment of such clinics.

WILLIAM A. YOST, JR  
Wauwatosa, Wisconsin

October 29, 1975

Introducing myself: male Caucasian, now at three score and ten, very active athletically through college, from high school through earlier business years 190 pounds--6 feet, health excellent until near age 50. Very happily married, one son who is successful attorney and business executive.

Some 20 to 25 years ago I developed a very "troublesome" ankle. My physician at the time, now departed, knew essentially nothing of arthritis (in common with the great majority). Finding that cortisone relieved the symptoms, I was given ever increasing doses of each new cortisone derivative until, when I had literally reached a critical point, he told me that he had reached his limitation, suggesting that I consult an orthopedic surgeon. I was fortunate in getting an excellent doctor who was interested in arthritis. Through him, after one brief look at me, I was in the hands of an internist who was a rheumatologist. Then the first of a long series of hospitalizations (in which I have undergone 10 surgical procedures) where I have been examined by many and "Exhibit A" for dozens of other doctors, nurses, or just plain interested persons.

In my case case, these men have given me excellent care and are presently considering a new pair of knees. Although my condition made it necessary for me at age 57 to leave a post as a ranking officer of one of the largest corporations in the country, I feel that my time has been well spent. I worked with Wisconsin Arthritis Foundation, I have had hundreds of calls from or about other arthritics, I've stirred up some interest in bioengineering, was the subject of a newspaper story, have talked about

arthritis to several nursing classes, have made a living--and all this as a cripple whose longest move of the day is from a bed to a wheelchair!

Yes, with this history, I do have suggestions--and hopes.

- (1) Training professional persons who, not knowing enough to help, would have courage to make referrals to qualified rheumatologists.
- (2) Attracting and training more doctors to be qualified.
- (3) Better use of facilities of Arthritis Foundation;
  - a. As laymen (money raising, planning, etc.)
  - b. As doctors (to guide according to specialty)
- (4) Expanded research--a necessity
- (5) More encouragement to the training and use of Bioengineers and Bio-psychoengineers.
- (6) And, for God's sake, recognize the problem that exists.

(Implementing each of the above numbered items is obviously a function of location and circumstances.)

BEVERLY BARTLEIN  
Muskego, Wisconsin

October 1975

I guess the first thing you think of when you say arthritis, is "Pain." Well there's more to it than just the physical pain. There is also mental pain. Some forms of arthritis are a very complex disease. It can be very frustrating and very depressing. It causes mental anguish and pain, as well as physical.

I am very encouraged by Federal funds for Arthritis. But I would like to see most of it used for personal help for the arthritic, such as a hospital or clinic like they have in California, that not only would help with the physical part, but the mental anguish, too. The clinic could be open to all forms of rheumatoid diseases. Diagnosis could be given and whatever treatment the person should have for their particular disease. Also there could be a therapy department. But also on staff there should be a psychiatrist or a psychologist to help with depression and the acceptance of the disease. A very active person, I believe, has a harder time accepting and coping with the disease. When a person gets run down and tired and is in a lot of pain, it's easy for him to get to the point of giving up, not fight anymore. We have to have personal contact with these people, so we can encourage them to go on. To give them hope and to insure them there is help.

I know the price of such a clinic is high, but Wisconsin is one of the worst states to live in with arthritis, and the people here really need help.

I am also for funds used for research, but would like to see more spent directly for the arthritic; both physical aid and mental aid.

Also, I would like to see more family involvement. The families need both physical explanations and mental understanding. Families and friends do not completely understand what is going on with the arthritic. I'd love to see more families involved. Most arthritics that I've talked to feel the same way.

HENRY W. AND ROSA L. DUXBURY  
Tomahawk, Wisconsin

October 28, 1975

We both have arthritic problems but are still able to take care of ourselves, but know of nothing else for assistance except a nursing home. After seeing some of the older folks sitting in their rooms hour after hour, alone, with no medical help, there is very little desire to be there except by force.

Many living outside without advice and a source of help is a pathetic situation. We know of no reliable party that would not be more interested in their own welfare than ours, so we had to call our son in from Chicago to get our fall homework done.

How many nursing homes or hospitals have trained help for Arthritics? Many do not have proper training for their regular work. Many are overworked.

Every area should have a help unit in a county or community building with training and helping ability who has inventoried and visited all sick people in the area who are physically handicapped. These people need not be college graduates, but are vocationally trained. A central area representative should collect their information from local representatives. These could gain information by meeting with medical sources, nursing homes, local health officials, school boards, and other public official meetings. It would be advisable to have aid money for emergency problems.

Some older people are self conscious and refuse public assistance. Others make a practice of sponging for everything. Some need emergency contact or transportation. Most older folks are happier in their own homes with a little outside help, which would be considerably cheaper than hospitals, nursing homes, etc. Some cannot read or write.

The majority of the wealthy are only interested in increasing their wealth. This includes unions and employees that use poor judgment and help make the poor poorer. People in the lower bracket do not have time if they are making their own living.



November 10, 1975

We would recommend two representatives in each district office with a different vocational trainee added every summer. This depends on population type, living conditions, and individual income in each district.

Anything written in this letter is based on our conditions as Senior Citizens, what we have seen and personal opinions as former teaching educators.

We thank you for your consideration.

JAMES E. GINTHER  
Akron, Ohio

October 27, 1975

The officers of the Akron Area Chapter of the Arthritis Foundation have asked me to forward to your attention on their behalf a letter on how we would like to see improved services available to local persons with arthritis.

Akron and the tri-county area we serve does not have at the present time a medical school or a medical teaching facility other than the private hospitals which have resident and intern programs. There is available to our patients no arthritis clinic other than the general charity clinics operated by two of the hospitals. Akron has five physicians who restrict their practice to rheumatology, but four of them can accept no new patients. This means, in effect, that the vast majority of our local patients are seen by family physicians who may or may not be interested in treating such a chronic condition. Most of our patients are forced to go to the Cleveland Clinic or the Mayo Clinic, or other recognized arthritis treatment centers far removed from their homes. This provides an economic hardship on almost every one of our patients.

We can envision and would encourage your committee to envision one of the primary purposes of the National Arthritis Commission would be the establishment of teaching centers or teaching clinics where physicians may be instructed in the clinical care of arthritis patients and where patients may receive competent medical treatment on an ongoing basis.

Since our board of trustees is made up primarily of laymen, we cannot presume to suggest how under our present systems of delivery of medical services such treatment centers should be established. We can only assure you that in municipalities and rural areas removed from medical educational facilities, there is a crying need for the immediate establishment of such clinics.

We appreciate the opportunity of forwarding you this information and regret that it is not possible for a chapter representative to be present at the National Arthritis Commission hearings in Milwaukee scheduled for November 10.

Milwaukee, Wisconsin

November 10, 1975

FRANK KRYZENSKE  
Sheboygan, Wisconsin

October 27, 1975

The way I feel now, I wish I would never have to see a doctor for the rest of my life. Too many doctors don't know the first thing about treating arthritis. The orthopedic surgeon that advised me to go to Social Security and claim total disability didn't want to treat me afterward. I suppose he thought elimination from work would take care of it and didn't know what else to do. Or perhaps he was too busy to take care of all the arthritics.

There seems to be a tremendous amount of apathy among most doctors and, as another doctor put it at an arthritis meeting in Milwaukee a year and a half ago, that doctors need to be re-educated as far as treatment for arthritis is concerned.

This letter would be too long to describe what arthritis is like, but I can say there were times I would rather be dead, especially when a good doctor isn't around.

We need arthritis clinics like they have in Canada. We need more doctors who can advertise: "Dr. specializes in arthritis" -- who have a little compassion.

I would love to attend the hearing, but I am leaving for Florida the 9th of November due to arthritis.

BASILIO LOPEZ  
Milwaukee, Wisconsin

October 23, 1975

I would like to thank you for giving me the opportunity to express my opinion to the committee about the care of rheumatoid diseases.

Without denying the need for basic research and training programs, I think a great deal could be done utilizing the present resources of knowledge and personnel in a more efficient manner.

I would like to recommend the following for your consideration:

- (1) The creation of a regional register along the model for infectious diseases, to which dealing with rheumatic diseases with secondary impairment, disabilities, or both, could submit names of their patients.
- (2) The approach to the care of this pool of patients could begin with the evaluation of their impairments. It could begin with the consideration of social-vocational, mobility, or medical deficits. The evaluation and treatment of these problems could be performed in a great number of cases by paramedical personnel under the medical guidance of their primary physician.

- (3) The creation of centers graded according to the number and sophistication of services which could serve as referring centers for better diagnosis and treatment. These centers could also be used for training centers to upgrade the skills of physicians and paramedical personnel dealing with rheumatic diseases.
- (4) An invitation could be extended to industry to use the centers for evaluation of impairment and disability in patients with musculoskeletal conditions, as the settlement in industrial cases is one of the main causes for increasing the cost of care. The diagnosis made on many of these cases is osteoarthritis, which prevention, screening, and management in earlier stages could minimize the complexity of medical care.
- (5) Earlier use of vocational services and vocational advice to people in the beginning stages of the disease to prevent the common difficulty of trying vocational rehabilitation in middle age or advance cases; a hopeless, unrealistic affair.

I hope these comments will aid you in the forthcoming Commission hearing.

MRS. JANET A. BREITZMAN  
Milwaukee, Wisconsin

October 28, 1975

It is very sad indeed that in this great country of ours little is being done for the person suffering from arthritis, in any form. The amount of taxes we pay as homeowners goes for so many other things, such as politicians' salaries, when they could tighten their belts just like the rest of us have to do in these bad economical times.

Arthritis runs in our family. I am 38 years old now, and what does the future hold for me? I have a son 17 who has already shown signs of arthritis in his knee; what does the future hold for him? I have a father 74 years old who has become almost bedridden because of this terrible disease. Here was a big man who always was very independent and now he has to be dependent on others around him, which makes the disease even worse because he is not a complete man any more.

Surely some of the tax dollars spent on foolishness could be put to some kind of good work in research for arthritis. Surely with all the great work done in medicine and research more could be done for arthritis. The thing about arthritis is that a person can live on and on and on and on with it for years and years and years and never get any relief from the disease, whereas with cancer, if you have it, in some cases, the only recourse is to die; then at least the person is not suffering any more.

Let's get on with it and do something for arthritis--let's think of the future and of the people who are suffering now, right now.



Milwaukee, Wisconsin

November 10, 1975

MRS. R.G. BURKE  
Milwaukee, Wisconsin

October 27, 1975

I am writing this with a ray of hope that finally our Government is going to recognize the very big need of the millions of arthritics. I myself am 67 years of age and am able to say that as far as my health is concerned, it is good. BUT--I am in great pain and am living with the constant thought that the insidious disease of rheumatoid arthritis is gradually taking away my love of life. My mind wants to do so many things that my hands and legs can't do any longer. I have already had one knee replaced in order to be able to function. There should be no limit as to what the Government should be willing to do in the form of constant research towards the prevention of this vicious disease.

Also, for those that already have arthritis, there should be funds to train doctors to become rheumatologists. There are so few available, and most people depend on their regular doctor to help them and they are not trained or equipped to do so. In my case, I lived in Arkansas when my disease was coming on, and although I kept going to my doctor and telling him how I felt, he did nothing about it and made me feel it was all in my head. There were no rheumatologists there. Thank goodness my husband and I had enough sense to leave there and move to Milwaukee, where I am one of the few lucky ones to be under the care of Dr. Gerson Bernhard. If I hadn't come to know him, I would have been an invalid by now. Most of the people I know here, even who have arthritis, go to their regular family doctors. There should be some kind of a program to educate the people to know that they should seek the specialized care of a rheumatologist. However, there are going to have to be a lot more doctors trained to be rheumatologists in order to meet the demand.

Up till now our Government has not realized the great need for helping all of us arthritics. I am sure the fact that Mrs. Ford is one of those suffering from arthritis is why President Ford has become aware of the great need of us arthritics. I hope the Commission can do something to relieve our suffering. Milwaukee, Wisconsin

PAUL C. CZECH  
Wauwatosa, Wisconsin

October 27, 1975

One of the needs is to have more money for research and the training of professionals to diagnose arthritis.

Information should be made available to people who suffer with arthritis, as to where they can get the needed help and what can be done to ease the pain.

Medical professionals and allied health professionals should be the ones to go before the Commission.

MARCIA DeBENEDICTIS  
Cedarburg, Wisconsin

As a sufferer of rheumatoid arthritis for six years, since my mid-thirties, I strongly urge more research into the cause and cure of this painful debilitating illness. As a victim, I need more information on the progress of the disease and methods of self-care. I strongly desire a cure so that I can live an independent, fulfilling life in the service of my family and friends. Also, there should be more information on possibilities for employment for the arthritic.

The disease is not dramatic as are the killer diseases such as cancer and heart trouble, but in terms of human suffering, it is beyond my comprehension why it goes unnoticed and undefended in the public realm. Not until it strikes in a home does a person know the cost in suffering and inconvenience to family and community. Please, please fund more money into care and cure so that millions can function in a normal contributing way.

HENRY C. FRIEND  
Milwaukee, Wisconsin

October 21, 1975

This is in reply to your letter asking for a Statement in connection with the hearings to be held by the National Commission on Arthritis to be held in Milwaukee.

It appears to me that more funds should be devoted to basic research in osteoarthritis. My physician, who is a specialist, does not know what causes it, nor does he know how to cure it, nor is he able to arrest its progress, even though I consulted him at an early stage of the disease.

If our science can put a man on the moon, it should be able to find the cause and cure for osteoarthritis if given sufficient financial and other support.

PAUL W. HAYDEN  
Slinger, Wisconsin

October 26, 1975

As a person who has lived with severe arthritis for over 10 years, I wish to thank you for recognizing this little understood disease and organizing a Commission to help understand and combat this problem.

I see that the problems of those injured by arthritis seem to fall into these major areas:

- (1) LACK OF KNOWLEDGE: General Public Education is needed to alert business, industry, and family to the signs of approaching arthritis, its early detection and treatment, its chronic nature, the fatigue and limitations it places on people. We now recognize the problems of high blood pressure and alcoholism. Can we say as much for arthritis? It robs from the very young, middle aged, and old in all segments of society.

- (2) LACK OF FUNDS FOR RESEARCH: We have institutes for all other major diseases, yet Federal and State funds are not so readily applied for extensive, formal clinical research which might relieve the suffering of millions.
- (3) LACK OF ATTENTION TO PROBLEMS OF THOSE AFFLICTED IN WISCONSIN WITH ARTHRITIS: Patients with arthritis find "normal" life difficult. Buses, shopping centers, theaters, public parks, churches and street curbs or steps are almost completely out of the question for wheelchair and crutch patients. Everyday activities such as buttoning, zipping, lacing, tying, typing, and raising and lowering from a chair are major obstacles. Bathrooms and stairs need lift bars and rails.

If we could gain FUNDS to: (1) educate the public, (2) promote research, and (3) expand public facilities to include materials for the disabled we would be taking a giant step. If other funds are available, they could also be used to aid patients in treatment, transportation, and daily life problems.

MRS. MARGUERITE HEMMENT, R.N.  
Lake Geneva, Wisconsin

October 27, 1975

Thank you for the notice about the Arthritis Commission hearings in November. I shall try and be present. Noting that you request Statements from people who have arthritis, I might mention that about a year ago my situation was diagnosed as R/A. If I had not had expert handling of diagnosis and supervision, I may not be able to type this letter. The sometimes insidious and capricious crippling aspects of arthritis can be much, much less with the support of the above. I am eternally grateful for the help that has been sent my way from all sources this year. As I am becoming a bit lengthy in my note here, I shall try and come to the point and to suggestions for using additional funds to combat arthritis--perhaps this is already being done. I do not know.

- (1) Have Mobil Arthritis Clinics like large campers--supposed to be quite successful in British Columbia, Canada. They reach people in rural areas that might not get to larger cities for needed medical help.
- (2) TV or radio commercials--to make people aware that they should not settle for anything less than expert medical help and not to rely on "home remedies." Also, do not settle for a blase diagnosis if you continue to have aches and pains and are turned away when you feel as stiff and achy as a wind-up clock by something like "you know as one gets older . . ." or "it's rheumatism . . . buy some Ben Gay."
- (3) Job clinics for arthritics.



Milwaukee, Wisconsin

November 10, 1975

VERA A. KLOPPMANN  
Milwaukee, Wisconsin

October 22, 1975

I most urgently suggest that funds be made available for a concentrated attack on the disease of arthritis. A program, in addition to what is now being done, should be set up for research to determine the cause and, hopefully, cure, or at least control, of arthritis.

More people must be made aware of the crippling nature and excruciating pain of this disease, and training must be done to offer aid and care for its victims.

I have a personal interest--my mother, a proud and independent woman, had arthritis of the spine and ended her days almost completely helpless. I too have the disease, although so far it has not progressed to a serious degree.

MRS. AUDREY J. KRUSE  
Milwaukee, Wisconsin

October 30, 1975

I will be unable to be present in person to attend the public hearing which will be held at the Marc Plaza Hotel on Monday, November 10, 1975.

I am, therefore, taking this opportunity to write my personal thoughts to you in advance of the hearing. I have been an arthritis sufferer for the past seven years and anticipate being one for the rest of my life. In 1968, I was diagnosed as having degenerative cervical arthritis. On several occasions since that time I have been hospitalized or received out-patient therapy for various forms of arthritis: bursitis, tendonitis, and diffuse fibrositis (muscular rheumatism). For the past three years I have had the benefit of a home whirlpool, which I use daily and find quite helpful.

To my knowledge, there is no known cause of or cure for arthritis. Therefore, I feel the most important aspect of this hearing is to decide to spend any additional funds for research so that this dreaded disease will eventually be conquered. It is also my understanding that there is some evidence that this disease is hereditary. In my heart I would like to believe that it will not be necessary for my children or my grandchildren to suffer the pain and discomfort that I have for the past several years.

JOHN H. LINK  
Evanston, Illinois

October 15, 1975

We are deeply concerned in Chicago and vicinity with the prevalence of disabling arthritis among not only the older people, but the very young and the middle-aged. The Illinois Chapter of the Arthritis Foundation has accomplished a great deal in providing services and funds for projects relating to patient education, patient care and diagnostic clinics, medical research, medical referrals, nurse practitioner training, but there is a limit to what we can do.

I hope in all sincerity that the Administration and Congress will take affirmative steps in voting an appropriation to make the Arthritis Act a reality. The Commission will bear an important part in this regard as well as other phases of the Act.

I will look forward to real progress in our effort to find the cause and cure of arthritis, and I am sure much credit will be given the Commission if it fully performs its purpose and obligation.

MRS. ANGELO MATTIOLE  
Kenoshi, Wisconsin

October 23, 1975

As a victim of arthritis for the past 30 years, I feel it is necessary to begin extensive research into such areas as cause and treatment. Additional funding by our Government should be eminent. If our Government can afford the sophisticated allotments for research to study such things as the tapir (a piglike mammal of tropical America), I would assume we, the millions afflicted by arthritis, deserve at least an equal allotment. We do need to become vocal. Our elected officials, I feel, have an obligation in trying to meet our needs. I conclude with the thought that the arthritis should be every man's concern.

MARY MENGEL  
Fond du Lac, Wisconsin

October 29, 1975

I have been an R.N. for 20 years. I have worked as an obstretic nurse. I would like to think that not being exposed to medical nursing would be an adequate explanation as to why I was so dismally stupid about anything and everything related to arthritis.

Eighteen months ago I was diagnosed as having a musculoskeltal disorder. It made me realize how very little I knew about any arthritic disorder. What little I did know came from aspirin commercials. The public, through the use of these commercials, are conditioned to think that arthritis is some inconveniencing pain that can be quickly eradicated after taking this special manufacturers product. Then bingo, back to a state of health.

When you think that probably a large segment of the public could give you the seven danger signs of cancer, are aware of connections between cholesterol and cardiac diseases, has clinics sponsored by health agencies to aid in the awareness and detection for diabetes and hypertension, and when it comes time for arthritis, the most of their informantion (inacurrate and distorted) comes from commercials, then surely we must realize that we cannot be proud of our continuing education but must come to the realization that virtually there has been no education in this area.

Monies spent on research and training is certainly money not wasted. However, I am sure that there is an abundance of knowledge that could be utilized by the public and health personnel if this knowledge would be

made available to them. This, I believe, should be the number one priority in allocating the distribution of funds.

Secondly, my physician sent me to the Mayo clinic to be diagnosed. A waste of money, and time when you consider that County General in Milwaukee has excellent people to whom I could have been referred, had they been aware of this. Obviously, this tells me that the physician in my community was not aware of what resources he could have tapped. Money should then be allocated so that people with expertise can share this with their fellow physicians. Seeing as arthritis affects so many of the elderly, maybe it would be a good idea to spend money passing a bill that no doctor could receive Medicaid or Medicare payments unless he had attended a conference about arthritis, say like every two years. This at least would keep doctors who weren't expert somewhat up to date. Of course the bill would have to have some teeth in it, like the conference would have to be attended in his district so he would become familiar with the resources in his area. One wouldn't want him to attend a conference in Florida in January. Somehow it wouldn't have the same effect.

I think that better care and treatment will be a natural follow-up to education. Let us not, however, forget what an important part a well trained nurse could do in educating and helping arthritis. Right now most state laws place too many restrictions on her autonomy. It is very difficult to change the entire Nurse Practice Act, but under the implimentation of the National Arthritis Act, certain specifics could be outlined that would allow the R.N. to better utilize her skills in caring for the chronically ill arthritic.

MRS. WENDEL NELSON  
Green Bay, Wisconsin

October 28, 1975

I am writing to you in response to a letter received by me concerning sending written statements in regard to opinions on specific needs in the National Arthritis program.

I have osteoarthritis. I live in Green Bay, Wisconsin. There are hopes by many of the Green Bay arthritics that more doctors would specialize in the treatment of arthritis and related diseases.

Also, our "dream" is to have a clinic in Green Bay to take care of this city and surrounding territory (Milwaukee being the closest treatment center).

There is a need for therapy programs geared less expensively than now to those persons needing these services. (In lower income, programs are too expensive, often for those most in need of the therapy programs.)

Then, and certainly of great importance, is the need for money for research to find the causes and cure to these crippling diseases. Aside from the crippling in many cases, there is much work loss and impairment in enjoying life to its fullest in many many cases of arthritis. Research to me is the "Biggie," not only for my generation, but for future generations that will suffer these diseases. Already we have many many



Milwaukee, Wisconsin

November 10, 1975

young persons having arthritis and showing signs of the coming afflictions.

In summary, we need money for research, for treatment, for patient education, for establishment of treatment centers, and for staffing of those centers. We need publicity through the news, radio, and TV, so people become more conscious of ARTHRITIS AND RELATED DISEASES.

MRS. DORIS NERO  
Brookfield, Wisconsin

October 28, 1975

I have suffered with arthritis for the past 10 years and feel that the medical profession, at least the ones I have come in contact with, are not well enough educated on this disease to adequately treat the arthritis victim.

Therefore, I would like to see more money spent on research and education. Research to find a possible cure, or at least adequate treatment to control the disease, and education of our medical profession so they will treat it as other than a headache that will go away with the administration of aspirin.

It has only been recently that I have seen articles in the newspaper, magazines, etc., regarding arthritis. I would like to see more of these also, as it is very difficult for family members to understand the limitations of the arthritic person because they also feel that is is a condition that is treated with aspirin and, like a headache, will go away. They do not understand that it is there all the time. This is all due to lack of education. I didn't realize it myself until I was confronted with it.

I don't believe it is possible to describe exactly what it is like to have arthritis. I do know that it is very painful and very frustrating not being able to do all the things you have done all your life.

I sincerely hope that we can get Congress to realize what a dreadful disease arthritis is and take some positive action.

MARGARET PANKRATZ  
Sturgeon Bay, Wisconsin

October 31, 1975

Through a friend I learned of the meeting concerning arthritis which is to be held on November 10, 1975. I am not able, physically or financially, to attend, but hope that my letter will contribute something to the meeting.

I am a 43-year-old woman with ankylosing spondylitis. It began six years ago in my neck and shoulders. Three years ago my left sacroiliac joint and left leg became so painful. Now my entire spine is affected.

To go into a detailed history of my trouble in finding a doctor who really knew what was wrong with me would take too long. The pain in my

neck was promptly diagnosed as arthritis here in Sturgeon Bay, but no one seemed to connect the two areas of pain (the neck and the sacroiliac joint and leg).

I spent a total of eight weeks in four different hospitals, from July 1972 to February of 1973. It was a Dr. Cammarata in Pittsburgh, Pa. who finally correctly diagnosed my problem as spondylitis. All this unsuccessful searching and various treatments cost my husband thousands of dollars. (I was not covered by any health insurance at the time, and now am not able to obtain any that will cover any trouble with my back.) How can the loss of a mother in the home be measured? It was so very difficult for my three daughters, and my parents and mother-in-law who "took over for me."

From February 1973 until January of 1975, I took 50mg. of Indacin four times a day and wore a back brace continuously. Then I developed an ulcer, so had to discontinue the Indocin. In May of '75, I started taking Motrin--400 mg., three times a day. By September my stomach was bothering me again, so it is the opinion of my doctor that I cannot tolerate Motrin either. My stomach is better now, but my arthritis much worse. Presently, I am taking two tablets of Tylenol four times a day and still wear my back brace constantly.

In January of 1974, my husband asked for a divorce, so I now live with my three daughters--ages 15, 12, and 9. It is difficult, and so far frustrating to try to maintain a house without a man, when I am able to do so little physically. I am qualified to teach kindergarten through 5th grade, but am unable to do any kind of work that requires any set hours and definite amount of time. Also any lifting, stooping or bending, sitting too long, or standing too long are out! My pain is constant, but unpredictable in severity, so some days I am able to do more than others. It is so very frustrating and difficult to accept.

It is my understanding that the committee would like some suggestions.

- (1) To me, it would be an answer to a prayer if scientists could only find the cause, and then perhaps the cure for arthritis. I have asked so many times--why is so little known about arthritis when so many people suffer from it? So I feel that top priority would be money for research!
- (2) I feel there is a great need for more doctors who are qualified to diagnose and treat arthritis. There is not one doctor who specializes in arthritis in the entire Green Bay area.
- (3) The proper therapy is so important and facilities so lacking. There is no place in Door County where arthritis patients can receive therapy. The therapy department of Door County Memorial Hospital is understaffed and inadequate. So I recommend that communities be made aware of this need and informed as to how this problem can be solved. Is there financial aid available, or must they raise the money themselves?

- (4) From my personal experience, I am so discouraged by people's lack of understanding and knowledge of arthritis. As you say in your pamphlet, we need understanding and encouragement. Not only that, but I feel that people are not going to do anything about arthritis until they are aware of the need. Through education and fund drives, people are now aware of the dangers of cancer and heart disease. Why not arthritis, too?

To sum it up, I would say that financial aid is desperately needed in research, training doctors, establishing therapy facilities, and educating all people--both arthritis sufferers and the general public--about arthritis. Everyone must become aware of all of these needs.

Now may I ask you, what can I do here in Sturgeon Bay to help? I am only too willing to do all that I can to help this prayer become a reality. I am sure there are many more like me, willing to help if we only knew what to do.

I pray that the meeting will be successful.

MRS. HOWARD L. SUMMER  
Racine, Wisconsin

October 24, 1975

One of the first things regarding the treatment of arthritis, I think, is to make more people aware of the existence of and the facilities offered by the Rheumatic Disease Center of Milwaukee. Also, there should be numerous centers such as this located throughout the United States, not just a few.

When I first heard of Dr. G. Bernhard and his associate, Dr. A. Goldman, I was unaware they were directly connected with Columbia Hospital and its facilities. Had I known that, I'd have been there sooner--believe me.

It's amazing how many people are ignorant that help is available and where to go for it.

I think a great deal of money should be appropriated to further the publicity--and ultimately the development of more of these centers.

God knows we need it. P.S. Whenever I've mentioned the "Rheumatic Disease Center" I always get the question, "What is that?" Then at least one more person knows when I explain.



Milwaukee, Wisconsin

November 10, 1975

MRS. DOROTHY THIELMANN  
Chilton, Wisconsin

October 24, 1975

I am 55 years old and have lived with severe rheumatoid and osteoarthritis for the last 8 years. I have taken every kind of medication there is.

I would like to have Congress pass a bill, supplying the Arthritis Foundation with some money for research to help find a cure for arthritis.

I would like to see our scientists work with foreign scientists. In this way they would accomplish a lot more in research. Does our Government want to support all the people who will be disabled from this dreaded disease? Let the Government help us, before we are disabled, by giving more money for research.

Why don't we have a telethon with local talent? This way we will keep most of the money in the community for the Arthritis Foundation. I also think we should send out little flags and have people send a donation in for them.

I read in the newspaper that Dr. Roger Wyburn-Mason from London has discovered the cause and probable cure for rheumatoid arthritis. He found this while at Yale University. Couldn't we learn a lot from Dr. Roger if our scientists worked together. I would like to attend the meeting November 10, if I can get a way to Milwaukee with someone.

ROSALYN J. VIG, R.N.  
Viroqua, Wisconsin

October 24, 1975

I certainly wish I could appear in person, as my writing ability is not up to par with the P.R. men or the journalists.

I became a victim of rheumatic arthritis approximately one (1) year ago. The onset was very sudden, or so it seemed to me. I had been in perfect health until that time. My age then was 51. After spending 30 years in the field of nursing, and raising three sons, two to maturity and one 12, I was aghast when I could not get out of bed one morning. Fortunately, my physician husband took me to the hospital where he turned me over as a patient, to an internist and rheumatologist.

Oh, yes, I had taken care of many patients with this disease before, but until I became a victim, I truly must say that I did not know the pain, stiffness, immobility, and emotional shock this could give to its victims.

I am happy to report, I was one of the fortunate ones, in having an excellent medical team, even though I had to travel 150 miles to get it. This leads me to question whether some of the money could be spent on a more local level, such as our 100 bed hospital. Certainly we should have steam tents, whirlpools, and such. Also, in small towns I believe a more in-depth history can be obtained.

I beg of the National Committee to please consider research training (M.D.'s or R.N.'s who have had the disease). Setting up group centers in all county seats, so people can feel free to discuss this illness and gain understanding and information about it.

The news media, such as T.V. and newspapers, should be forced to give onehour programs on this topic, as I understand millions of hours of work are lost annually because of lack of proper treatment. Continuing education of physicians, nurses, and patients, and ancillary help.

What should be done?

T.V. is your greatest media, as well as newspapers, medical schools, nursing schools, and business industry.

In fact, everyone should be involved. The public needs protection against quack medicines and quack healers. I consider this a very urgent problem.

Let's get everyone involved. If we can spend \$1,000,000, for an airplane, why not for something that is causing so much human misery? Where do we fit in?

Maybe Congress should know that 15 million Americans have some form of Arthritis. That is a powerful tool when it comes to voting. I just hope they are aware of this.

Also, I think Congress, getting free medical expenses themselves, don't know a darn thing about the cost of being ill with arthritis or the cost of the medicine and treatment itself. I just feel we had all better get some of these priorities straight.

I thank the Commission for listening, and again, instead of being negative, let's keep our own well.

CHRISTINE VOIGT  
Kenosha, Wisconsin

October 26, 1975

Upon receipt of your letter of October 17 1975, I called both members of W.A.F., as well as friends in Racine and Kenosha, to write letters for presentation to the National Arthritis Commission on November 10th at the public meeting in Milwaukee.

We all feel that research is necessary and yearly funds should be established to search for the cause of arthritis to help not only those currently afflicted but those who will develop same and enable medicine to find disease in early stages.

I feel a contributory factor to not only arthritis is varied and many questionable additives in our daily food allowed by the Food and Drug Administration. When refrigeration was in its infancy, perhaps the additives were necessary, but today--WHY?? Are the many questionable

Milwaukee, Wisconsin

November 10, 1975

additives necessary to preserve shelf life of food and endanger the life from the crib?

I also feel that medical students should have more knowledge so that as doctors they will be more qualified to help the arthritic patient other than aspirin every four hours or until your ears ring!!!!

ROBERT J. WILSON  
Madison, Wisconsin

October 29, 1975

Due to the unusual nature of the arthritis disease and the frustration individuals have in attempting to relieve their ailment, I deem it most appropriate, if not necessary, for the Government to assist in the support of programs to develop cures for the disease as well as help educate the populace as to the present treatments available.

Funds provided for research at the University of Wisconsin have resulted in successful procedures, treatments and insight into the care, prevention, and cure of those afflicted with the disease. A continuation of the program is dependent on funding that will allow the further study and research necessary to help provide a healthier existence for the people of our country.

It has been my experience to see the relief a few of my personal friends have obtained from proper treatment and care of their disease. It is important that more people with the disease be given the confidence and knowledge that with proper and professional care arthritis may be cured or substantially relieved in many cases.

Thank you for your consideration.

CHRIS WRUCK  
Milwaukee, Wisconsin

October 29, 1975

In response to your letter of 10-17-75 regarding the unmet needs and "What it's like living with arthritis."

Living with arthritis is like living with a demon who at any time will apply pressure on areas where you have arthritis. The affected areas become stiff, sore, and, at times, immobile. There is no known cure, only medication which at best is only a temporary relief. In most cases exercise is a must, unless you want to become stiff and remain that way.

There are many unmet needs and much money is needed for research to obtain either a cure or better treatment and care. To meet these needs, help is a must from the Federal Government funds.



Milwaukee, Wisconsin

November 10, 1975

MRS. ELEANOR ZOLORSKI  
St. Francis, Wisconsin

October 21, 1975

Being a person who has arthritis, and having a dear neighbor who is crippled with arthritis, I am deeply concerned and interested in everything that goes on pertaining to arthritis.

I think continuing education is very important and more money should be spent on this. The classes we had at St. Lukes Hospital were very helpful, and the therapists were wonderful.

Better care and treatment diagnosis is another area.

I think one very important area is to try to reach people with arthritis young and old, who are unable to leave their home, and try to educate them to help themselves. I think this group of people are apt to be forgotten, because no one speaks up for them.

I would like to see medical professionals articulate before the Commission, because they have the knowledge. Also, I think people with arthritis should speak before the Commission. More, much more, money should be spent on research to find a cure and not just a panacea for arthritis ailments.

Like any other disease the public must have continuous reminders about this dread disease, arthritis.

MRS. KENNETH RITTER  
Cedarburg, Wisconsin

November 11, 1975

For years people have been blaming pains in the joints or back or wherever as arthritis and shrug their shoulders and just figure it is something they have to live with. And because the pain isn't constant, it has been ignored by medical people and patients themselves. Many people are made to feel like chronic complainers, especially by industry and even loving family members.

Osteoarthritic people, especially, are ignored because there is usually no visible outward signs. Therefore, it has been ignored as far as research into the cause; and cure has been nil for so long. Very few doctors have been interested in it and a very defeatist attitude has developed about arthritis and rheumatism; even bursitis which can be extremely painful.

So much needs to be done yet in research, treatment, and education about the progression of arthritis and what develops. Industry and labor has to be trained in ways of running factories or offices with equipment that relieves constant stress on joints and the back. Also, having employees learn more than one type of work so a rotating system can be used. Factory management can be very stubborn about this.

Personally, I am trained in office work and factory machine work. Management has a misconception of the ability of their people to learn

more than one procedure. Boredom and tiredness from doing the same thing all the time reduces productivity much more than the short time it takes to train someone for a job. They have a tendency to look down their noses at the so-called common average person. Nine times out of ten the average person has a wealth of know-how far superior to some of the people in a management position. Politics plays a great part in promotional activity --not necessarily the person most qualified for the job.

You'll also find management has the comfortable chairs, the plush carpeting, and fancy desks. They need these luxuries the least.

Cushioned rubber mats on concrete floors, adjustable work table heights, and adjustable chairs are much more necessary in a factory or office.

A good example is my husband, who is 6 feet, long-waisted and legged. I am 5 feet. We definitely are not comfortable in the same chair. At home you can purchase what you need. In the work world you have to take what you get, unless you have reasonable people who understand.

Industry needs a great amount of education in the area of not treating the human body as they would a piece of their machinery. In fact, they are much more concerned about their machinery than they are about the people operating it. This is partly the reason people have a "I don't give a darn" attitude about the kind of work they turn out. All they know is what they do isn't really appreciated, and therefore, a depressing rather than cheerful attitude prevails. This attitude is just as detrimental to the victims of arthritis as the actual work.

A panel of representatives from each of the fields listed on your form with several people who have the different kinds of arthritis should articulate before the Commission. We can tell about it more than anyone else and the frustrations that go with it.

We need to stop being used as a football between the insurance companies and the doctors.

JAMES SCHLEVENSKY

October 22, 1975

I am a 58-year-old man who has R.A. I have been disabled for 3 1/2 years and am one of the lucky ones who, because of excellent care by two Milwaukee doctors, am still able to move around and walk to a limited degree.

My feelings on what the Commission should do to help in addition to research, is to help finance young doctors to specialize in the rheumatoid diseases. Educate employers that an arthritic does still have his brain power and can do limited work. I have found that when I apply anywhere for part-time work that the minute I mention R.A. everyone, including the rehabilitation division in Wisconsin, because R.A. is incurable, they back off and say "Sorry."

Milwaukee, Wisconsin

November 10, 1975

LEWIS STARK  
Madison, Wisconsin

November 18, 1975

On November 10, 1975, a hearing was held by the National Arthritis Commission at the Marc Plaza Hotel in Milwaukee, Wisconsin. Unfortunately, I was not able to attend the hearing. I was informed, however, that a written statement to you could serve the same purpose.

I have rheumatoid arthritis, with multiple residual deformities and effects and am totally confined to a wheelchair. My experiences with arthritis, however, are not that different from the millions of people who are in similar positions. I wish to address my statement to the need that people like myself have for continued extensive contact with Vocational Rehabilitation agencies. Since I am now a rehabilitation counselor, my opinion may be somewhat prejudiced in regards to the importance of early and continued case services from Vocational Rehabilitation. On the otherhand, though, it seems all too clear to me that the rehabilitation needs of people with arthritis as well as other people with deteriorating progressive muscle disorders and similar debilitating conditions are special enough to warrant a discussion and some long-term consideration.

When a person is afflicted with a progressively deteriorating condition, it is my opinion that he may be involved in any number of different vocational rehabilitation plans. Since it is apparently impossible to determine the extent of disability which a person ultimately may reach, it seems to me it is impractical to work out a rehabilitation plan with a client that will prepare him for this ultimate disability. In my own case, before I was able to achieve my present position, I was involved in various rehabilitation plans. When I was confined to bed, I was involved in correspondence courses, homecrafts, and similar situations. When my disability finished its progressive course, I was able to participate in a college program in a wheelchair. My point though, is that at the time of each level of disabling progression, I could not believe that my disabling condition would procede to what in fact were its ultimate limits. Consequently, I would not consider any vocational plan that would prepare me for this ultimate condition. I feel that other people similarly afflicted would have similar problems accepting alternatives before this alternative became physically necessary.

In short then, I would very much like to see more and more intensive VR services provided to people with progressively disabling conditions, to help them at their present physical levels, and perhaps prepare them to achieve some sort of meaningful existence in spite of their disability or its ultimate course.

Thank you very much for the opportunity to address this statement to you.



MRS. MYRTLE M. BERG, R.P.T.  
Beaver Dam, Wisconsin

October 27, 1975

As a person with arthritis and a physical therapist, I want you to know how important it is to continue help for the arthritis victims of Wisconsin. Arthritis is one of the most common patients I treat, and I have found how important the literature distributed by the WAF and the educational meetings for the public are, to inform them that something can be done.

As a therapist, I was able to attend educational meetings for continuing education credits for the past three years. Through these classes and by being an active member of the WAF, I found out what could be done for arthritis. So, when I found out a year ago that I had osteoarthritis of the knee, I wasn't frightened, but clued in on everything my doctor told me as to what was happening to the joint and what could be done. Without this previous knowledge I would have hesitated and would have been frightened about my future--as I could not have continued my present profession. I now have plans to have a total knee replacement and anticipate a normal function of my knee again.

So I feel it is imperative that the arthritis diseases have continued help in education and research to keep up with informing the public and professionals.

As a therapist, I have worked with the WAF to plan and assist as a consultant, with sessions for people in this area, to find out about arthritis.

The students from the U. of Wis. Occupational Therapy Department with their advisor, Mrs. Kirnat, have had three different series of sessions. These sessions were for people in this area with arthritis. It gave information, demonstrations on ways of making activities of daily living and recreation easier to do, and to impress upon people how to live with arthritis without aggravating it. These classes were extremely valuable and well received. Recently, the director of our senior citizens called me and asked if we were going to have another class, as she had had some inquiries about it. She would like me to have a repeat of our previous session. So I am having her send out a questionnaire to see how many are interested, before planning anything. So to me this shows that we are constantly needing to help new people and should have this type of program available.

Wisconsin, and especially my area, seems to have a high total of the population with some form of arthritis. I hope the Commission will increase the funds and improve services to our arthritis victims.

LOIS BLANK  
La Crosse, Wisconsin

October 30, 1975

The most prevalent concern for the arthritis population is the lack of community arthritis screening, treatment, and education. In western Wisconsin, a predominantly rural area, there are many arthritic patients living quite a distance from a rheumatologist and expert medical care for their arthritis. There must be more education to general practitioners or have screening clinics located in these rural areas.

The treatment my patients have received in the past is often very inconsistent and contradictory between various doctors and clinics. The patient becomes increasingly skeptical of any treatment and more likely to try a self-determined treatment; i.e., quackery. Public education is by far the area that needs your attention at this time; public service announcements directed toward eliminating quackery and urging the public to consult arthritis specialists or educational classes. Presently, there is a lack of appropriate printed or audio-visual media available for the general public.

Arthritis definitely needs more national attention to improve the quality of care to a much neglected segment of our population.

MRS. MINA I. BOSSHARD  
Janesville, Wisconsin

October 25, 1975

I am 73 years old and have had arthritis for 15 years. My last x-rays show that I have advanced arthritis (rheumatoid) throughout my whole body, but I can still walk a few steps with a walker. I have been very fortunate that we have had the means for me to have good care and excellent doctors. When I could no longer care for our home or prepare meals, my husband and I came to Cedar Crest Health Center, Janesville, Wisconsin (five years ago). My husband had heart trouble and diabetes. He passed away in June of this year.

To my mind, more research right now is the most important need now. I was told sometime within the year that the Chicago Tribune carried an article about some scientists who had found a link between arthritis and measles. I had measles three times (red measles, German measles, and liberty measles). It set me to thinking how wonderful it would be if children could be inoculated with a shot intended to immunize against arthritis.

Along this line of research a questionnaire could be sent to known arthritics asking what childhood diseases they had had and what illnesses prior to the onslaught of arthritis. I suggest a public campaign for funds. Perhaps the Government would support it, too.

Other suggestions: (1) Continue the self-help classes, (2) Prepare a booklet to send arthritics making them understand the disease better. For instance, it has been said that when they grieve over the loss of a loved one, arthritics get worse. True? If one knew this might happen (as I did not) they could probably take it better. (3) Ask the public to bring into

an equipment pool unused crutches, braces, wheelchairs, walkers, etc., (4) Make a survey of arthritics who have had surgery to find out how successful it has been, and (5) Make a booklet of exercises free to anyone who writes for it.

Several years ago I signed up with the University Medical School, Madison, Wisconsin, to donate my body. I hope in doing so more will be learned about arthritis.

MRS. ANN BULIN  
Milwaukee, Wisconsin

October 1975

One picture is worth a thousand words. So does one physical therapist of the hospital self-help classes that are sponsored by the Arthritis Foundation.

Hospital surrounding, medical authority, not just words on paper to read, leave an impression on what the Arthritic Society is trying to do to help us arthritics. Everyone that has gone to the classes at the hospitals say that is the most helpful information they have received anywhere. Anything we can learn to help oneself gives encouragement to continued treatment of arthritis conditions. This type of self-help instruction should be expanded and advertised more. It is money well spent. Keep up the good work, and we arthritics will keep telling everyone how the Arthritis Foundation helps us.

MIMI CHERNOV  
Milwaukee, Wisconsin

It is not my purpose in writing this to recount my personal history as a person with arthritis. (I do not use the word arthritic since this defines me solely in terms of my illness. I like to think that there are facets of this person I call me that are more interesting and more valuable than a disease.)

It is necessary, though, to identify myself as having rheumatoid arthritis, since it is out of the particular experience of the illness that I have evolved strong opinions and formulated attitudes concerning various needs: those of persons having a rheumatic disease; those of persons who, according to projective studies, will one day have a rheumatic disease; and those of the health-care professionals who treat this large segment of our population.

While my personal and most intense concern is for the emotional well-being and psychological health of chronic-disease patients, I will deal first with some basic problems facing this Commission.

1. There is a tragic lack of public education in the field of arthritis and related diseases. I look with envy at the public relations campaign of the American Cancer Society. Who among us is any longer unfamiliar with the seven danger signals of cancer? How many lives have been saved by the reassuring knowledge that death is not the inevitable



outcome of a diagnosis of cancer? But what does the American public know of arthritis? We know, from television commercials, that one need not seek medical advice for the minor aches and pains of arthritis. One need only to swallow a couple of aspirin tablets when one hurts, and then get on with painting or gardening or whatever makes one happy! On the other end of the haphazard spectrum of public education we have the charity appeal, trying to wring money out of an already illness-sated society with pathetic and frightening pictures of cripples, "victims," and "sufferers" of this "most disabling of all diseases!" Is there a truth somewhere between? Can the public be educated to the need and efficacy of early diagnosis and proper medical treatment?

I urge that the Commission recommend the allocation of funds sufficient to mount a nationwide public education campaign, utilizing professional public relations expertise, for the purpose of disseminating factual information and sound medical advice.

2. There is a dangerous lack of knowledge of current research findings, including medications and procedures, among physicians other than those specializing in rheumatology. I am offended by the fact that there are persons suffering needless pain and the disabling effects of arthritis because they are under the care of a physician who does not have the necessary information to treat them properly. The body of knowledge concerning the rheumatic diseases has grown enormously. In 1942 there were less than three dozen disorders listed in the Primer on Arthritis. The seventh edition, published in 1973, has almost three times that number. Obviously it is impossible for every physician to keep pace with the growth of knowledge.

Because I favor mandatory continuing education in general for yearly or biyearly recertification, I urge the Commission to support the concept of required continuing education. I further urge that the Arthritis Act supply the funds necessary to provide opportunities for continuing education in the rheumatic diseases for all medical professionals who in any way serve persons with a rheumatic disease.

3. There is a serious shortage of rheumatologists serving arthritis patients' needs in Wisconsin. According to information given to me by the Wisconsin Arthritis Foundation, the ratio of rheumatology specialists per patient population in Wisconsin is somewhat more dismal than that found elsewhere, especially on the East and West Coasts. There are an estimated 400,000 persons who have arthritis in the State. In Milwaukee, the largest city, we have six board certified rheumatologists. Of these, three at least spend more than half their time in research as opposed to patient care. I believe there are two board certified rheumatologists in Madison; however, one will be moving out of the State this year. Also according to the Wisconsin Arthritis Foundation, there are three board eligible physicians seeing patients. One can see by these figures that there are simply not enough specialists' hours to cover the needs of the patient population. Because of this, many people are forced to obtain treatment from an underqualified physician, or, if they are able to make an appointment with a specialist, it can mean two or three months of suffering between the time of calling the office and the time of the first appointment. The burden on the specialist must be frustrating as well as

exhausting, but I can only speak for the patient, who is prevented from obtaining proper medical care.

Historically doctors tend to locate in the area in which they served their last residency. It is vital, therefore, that Wisconsin provide opportunities for young doctors seeking residencies in rheumatology.

I urge the Commission to recommend that the Arthritis Act establish departments in rheumatology at both the University of Wisconsin Medical School and the Wisconsin College of Medicine. I suggest the allocation of funds for special grants to be used to create full-time teaching positions which would be financially attractive to leading rheumatologists. I further suggest that smaller grants be made available to top students wishing to take a residency in rheumatology. In this way training in rheumatology in a teaching hospital in Wisconsin would assume both educational and economic importance. Note: I suspect that there would be legal implications in Government monies being used to support these programs. I assume, however, that the Arthritis Act and the Arthritis Foundation will cooperate with each other, and that while the funds might be raised by the Foundation, they would be administered through the Arthritis Act.

4. There is a desperate need for programs that attend to the emotional and psychological needs of patients with rheumatic diseases. A diagnosis of a chronic and possibly disabling illness causes psychological pain. This pain is as real and as predictable as joint pain. I stated earlier that my purpose in writing this is not to recount my personal history. I must draw on my own experience to convey some of the feelings of a newly diagnosed patient. In my case, I changed within a few months from a healthy, self-sufficient, active woman with a full-time and fascinating job into a sick, pain-filled, dependent woman who was sad and frightened. From being a contributing member of society I became a "patient," in a strange and alienating environment where I was to follow orders, submit to surgery, given or denied bathroom privileges and all of the other passive and dependent activities the sick role implies. The very words and phrases set the tone of that role. Besides having to deal with pain and weakness and loss of mobility, I had to become a new kind of person. For me, as for many many other patients, this is almost an insurmountable task. Certainly it is not accomplished without great inter- and intra-personal problems.

As both an in-patient and as an out-patient, I found no fault with the amount of attention paid to my physical complaints. I happened to be one of the fortunate few who obtained the services of a rheumatologist. The "team" consisted of the rheumatologist, a nurse-specialist, occupational and physical therapists, physiatrist, and orthopedist. Who among this array of professionals helped me deal with the emotional turmoil of my illness? The rheumatologist had neither time nor training. The nurse, as in most cases, perceived herself as nurturing and mothering and thus would have increased my dependency needs. The physiatrist and orthopedist obviously spent only short periods of time with me. The therapists might possibly have seized the opportunity, since longer periods of time were spent with them, but they didn't have the proper training or skills.



Since no one was able to help me explore my feelings, I felt that the feelings were not things to be discussed. I felt very alone in having these feelings. I later learned that many of these emotions were so similar as to be typical for most patients. It is most helpful to know that others are experiencing the same feelings and pains, and that depression is as much a part of the illness as a physical symptom.

I believe that group therapy, utilizing a social worker or psychologist as discussion leader, can be most helpful. The use of a mature and emotionally stable patient as a co-leader is especially good in that patients will identify more with their peers than with a professional of any discipline. The advantages of group therapy are numerous. It gives patients an opportunity to express their concerns, to receive feedback from other patients about their behavior and adaptive methods, and it helps them realize that they are not alone. The understanding that no judgment is made regarding feelings, that there are no right or wrong feelings, but that there are healthy or unhealthy ways of dealing with them, is of primary importance.

Because I feel very strongly that the psychological needs of persons having a rheumatic disease are great, are normal reactions to an abnormal situation and therefore are not neurotic needs, and that there is nothing in the present delivery of health care that meets these needs, I strongly recommend that the Arthritis Act allocate funds to all programs treating those with rheumatic diseases for the express purpose of employing a social-worker or psychologist trained in group work. I further suggest that on-going group therapy be an integral part of such programs, with referrals made by the rheumatologist on the same basis as used in referring patients to occupational and physical therapy. I would encourage the identification and use of a patient as co-leader of the group, both to encourage such patients to resume a contributing role, and to help other group members feel more comfortable in the group.

Note: As a result of my background in group work and my experiences as a patient I have been able to establish a program of group therapy for patients of any chronic disability at the Mount Sinai Medical Center in Milwaukee. This program can easily be translated into one for only those persons who have a rheumatic disease.

Because our rate of success has been very encouraging, especially with our patients with arthritis, I am including, as Appendix A, a copy of an article written for the Wisconsin Arthritis Foundation which describes the program. I shall be happy to correspond with anyone desiring further information.

I am grateful for this opportunity to express my hopes and recommendations to this Commission. Thank you.



APPENDIX A  
Mimi Chernov, Coordinator  
Psychiatry Clinic's  
Mount Sinai Medical Center Psychiatry Clinic's  
Program "Living Adjustment Groups"

APPENDIX A Mimi Chernov, Coordinator, Mount Sinai Medical Center Psychiatry Clinic's Program "Living Adjustment Groups"

This is the cover of a brochure which tells about a program of the Mount Sinai Medical Center. The program, "Living Adjustment Groups for People with Chronic Illness" meets at the medical center's Psychiatry Clinic. It helps fill a gap which exists in the delivery of total health care services for the chronically ill or disabled person. On the inside of this brochure a patient is quoted as saying, "People were always trying to be cheerful around me. I got the impression that I wasn't really supposed to talk much about my feelings . . . but I was angry at being sick, and scared, and depressed. Worst of all, I didn't realize that my feelings were all very normal!"

How familiar these thoughts are to anyone who has a chronic disease. Illness always arouses anxiety. A diagnosis of a chronic illness, such as one of the rheumatic diseases, is particularly stressful. While excellent medical care may be available, there is little opportunity for patients to discuss their emotional reactions to being ill. Doctors are already overburdened with the task of diagnosing and treating the physical problems of their patients. While nurses and therapists may be helpful to the person who is hospitalized, it is usually at home, dealing with physical limitations on a day-to-day basis, that one faces the most trying frustrations. This can be a very lonely time, a time when the patient may feel isolated and alienated from those around him or her. It is a time when one needs the comfort of sharing concerns with other people who have personally experienced these very feelings.

The Living Adjustment Group program is designed to provide this opportunity. It is for people who are no longer in the protective atmosphere of the hospital. The groups provide a comfortable and caring situation in which everyone involved fully understands how it feels to be limited in any way by physical problems. The underlying philosophy of the program is that feelings of fear, sadness, frustration, and anger are not wrong or unnatural, but are perfectly normal reactions to an abnormal situation. No judgments are ever made concerning feelings, because it is felt that feelings in themselves are never wrong or bad, but that what one does with them can affect both mental and physical health.

The groups, which meet weekly for an hour and a half, are co-led by a psychologist and a caseworker who herself has rheumatoid arthritis. While members of the groups do not necessarily have the same illness or disability, the nonmedical problems of adjusting and coping with any physical limitation are similar. Within this nonjudgmental atmosphere, members freely explore their feelings and attitudes. Often simply talking about emotions will clarify them and help place them in a proper perspective.

The Living Adjustment Group program serves the particular needs of the members. As a crisis intervention program it is especially helpful to the newly diagnosed patient who is struggling with a new and changed concept of self. This is a particularly stressful period. Discussing vague fears and dire expectations with others who have lived through the same difficult time helps the new patient understand their fears may be worse than reality. Being with other patients who have come through the same, and often far worse, physical crises in a positive manner can be far more effective therapy than the well-intentioned words of a professional who has not personally lived the experience.

Value systems, or what is felt to make life meaningful, affect the patient's sense of self-esteem. Within the groups, there is unhurried time to examine both personal and societal value systems, and to reevaluate and alter expectations and priorities if necessary to improve the quality of life.

A young mother, Mrs. B., felt that she was failing her twelve-year-old daughter because she was unable to sew her pretty clothes as she had before her hands became swollen and painful with arthritis. Her sense of self-esteem was suffering badly. The group was distressed for her. Together, they explored other ways in which she could "do" for her daughter and feel good about herself. After a few weeks, Mrs. B. told the group that she was spending much more time just sitting with her daughter, talking and listening. She felt that they were really communicating, and that their relationship was growing closer. Incidentally, the daughter began to sew some simple clothes for herself, and Mrs. B. took great pride in this. She began to feel very good about herself as a mother once more. She had changed her value system, and in doing so discovered new dimensions of motherhood.

The program serves as an information and resource center for the members. Patients often find that they need more leisure activity to fill their time and their minds. Miss D., a teacher who had been forced to retire at a rather early age because of a heart condition, was feeling useless and depressed. She was not well enough to work regularly but was able to do some very light tasks. She was referred to the Wisconsin Heart Association, where she is now doing volunteer work twice a week. She is not only keeping busy, but has the satisfaction of making a contribution to the organization which is literally closest to her heart.

Many patients with physical problems find that they are no longer able to work at their old jobs. If it is feasible for them to be reeducated for another type of work, the Mount Sinai Group program will assist them in contacting the Department of Vocational Rehabilitation for evaluation and training.

Those who suffer from physical problems are not exempt from all of the other life problems that plague society. Marital problems, financial problems, difficulty with children--all of these worries can hamper the effort to regain physical strength. If a group member should at any time desire individual therapy sessions, this is easily arranged, since the Psychiatry Clinic offers a whole range of services.



While medical problems are not discussed during the group meetings, if the members want medical information, every effort is made to bring in resource persons who can provide it. Recently a group of stroke patients felt that they would like to discuss the cause of strokes, and a neurologist was asked to attend a meeting to speak and to answer questions.

Unfortunately there is no magic cure for chronic physical problems. But there is help for the troublesome emotional reactions that are a predictable and natural part of illness or disability. Early recognition and acceptance of feelings can prevent future emotional difficulties. Learning to confront and explore one's feelings serves to discharge some anxiety and lessen anger and guilt. In the busy world of medicine, there is seldom time for a satisfying, in-depth discussion of what is happening not only in the body, but in the mind of the patient. This can be frustrating both to the patient and to the doctor, since what affects a person physically also affects the emotions, and emotions play an equally important role in one's physical condition.

The Living Adjustment Program offers the opportunity for this kind of discussion. It is not a place to talk about aches and pains, but rather a chance to deal with emotions and explore ways in which to make them less troublesome. It opens doors to a life that, though it may be different, can still be fruitful and satisfying.

The groups are open to the community. Any person having any illness or disability who feels a need to talk, or to deal with the emotional aspect of the physical problem may join the program. Referrals are not necessary. As in all services of the clinic, fees are on a sliding scale, and are based on ability to pay.

For further information, or to become a member of a group, call Mount Sinai Medical Center, 271-8200, Extension 766 and ask to speak to someone regarding these groups.

LORRAINE COLLINS

October 1975

How can a person describe what it's like to have arthritis. It is an uncalmable pain that seems to tear joints and flesh apart as I am sitting here now. My spine is on fire with a tearing feeling. In the morning I am not sure I can walk down the steps because my hip and ankle joints hurt so much. At times I can't sleep or find comfortable positions to lie because I ache all over. This pain aspirin won't help. Usually after I'm up an hour or two most pain goes away. Except today the doctor has prescribed [Azold A] which I take when pain is too bad. I took [Azold] about an hour ago and have been up two and a half hours with no relief yet.

I worked in private homes, as well as an old age nursing home, for 11 years and have seen much arthritis pain and twisting of joints. I know exercise helps me and others for twisting of joints. I think wearing of splints would help joints from turning some. My arthritis flares up more in fall and winter, that I can't sweep my floors at times. I find an



Milwaukee, Wisconsin

November 10, 1975

electric blanket helps most in the winter, and I have thought of an electric pad to lay on instead which I think would help more, but never got around to it. I wish in nursing homes all physical therapists would have exercise to keep the joints moving more.

What to do and how I don't know, except that at our nursing home, "Gateway," at Hartford we have a therapist come in three times a week to help people once a day for a few minutes. This helps very little. They need to exercise several times and EVERY day if their health permits. Some have been still for years. I know they torture these poor souls because the State says Title XIX people can have help, too. These people really suffer when they are done exercising. I don't know how it can be helped otherwise.

P.S. In answer to your question what to do with additional fund, why can't this be used to train persons to go traveling to different communities to teach hospital and nursing homes of different types. Then these people can teach individuals to go home and help themselves. If there was a large center for patients to come and be treated, this would only help those who could afford it.

MRS. CYNDE FORBES  
Milwaukee, Wisconsin

October 21, 1975

I am strong, healthy, 35 years old, and happy, but I have one problem. I have osteoarthritis and rheumatoid arthritis all over. It is difficult to adjust mentally and emotionally to this fact without truthful information.

The Foundation still needs to give out information to teach the patient to adjust, to keep right on living, and how to pace yourself. They need to teach us how to cope with the everyday irritation, pain, and mobility restrictions.

They have helped me a lot, but once around is not quite enough because arthritis is every day, every month, and every year -- not just a once-around illness.

LYDIA F. FRANK  
West Allis, Wisconsin

October 23, 1975

As an arthritic, I feel there should be more research into causes and treatment of arthritis. The Government should be of more help.

We need monthly meetings and informed doctors as speakers, and also it would benefit us to have a social gathering where we could air our views and complaints. We could get out in the open all the "get well quick" cures and quacks.

There should be more publicity and information on community help, such as a low cost clinic, so people could be better cared for and informed or diagnosed. The health departments could have some part in it.

There are diabetic workshops; why can't we have arthritis workshops? The people to carry out these programs would be community service, hospitals, community funding sources, medical profession, people with arthritis, industry, and elected officials. A telethon might be a good idea. Thank you.

IRENE GIBBON  
Cedarburg, Wisconsin

October 26, 1975

My late dear mother was a victim of arthritis. She didn't die of it, a stroke took her, but arthritis made her last years painful and miserable.

I'm afraid I didn't do too much for her at the time. I was impatient and, at times, unsympathetic. I didn't understand a disease that allowed some apparently pain-free days, but at other times left her almost helpless.

Mother did not complain, but I can still see her pain-pinched face and hear her say, "Why can they send a man to the moon and yet not find something to help or cure this disease?"

Some of the medication she took impaired her hearing, and again I was short with her about that.

After I lost Mother in 1968, I became friends with a woman about my age in the 40's who is afflicted with this disease. I have tried to find out more about it, and I have joined the Arthritis Foundation in my Mother's memory.

Surely money spent to help the thousands of men, women, and children who suffer from this disease is money well spent.

One thing I think that would be helpful would be an agency to provide physical help for those afflicted. In later years my Mother could not open a can, vacuum, take care of her garden, even make a bed without pain. I did not live in the same Wisconsin city, and I felt badly that she was so alone.

A nursing home is not always the answer. She was happy to stay in her home and somehow she managed, but life would have been easier had her daughter and other people understood the nature of the disease and if some services had been provided by the State.

It's too late for my Mom, but maybe this letter will help others get help now.

MRS. FRANK HAMACHEK  
Keweenaw, Wisconsin

October 21, 1975

Those of us with rheumatoid arthritis do need a great deal of additional help in many areas.

I first was told I had rheumatoid arthritis in January 1969 (correct diagnosis by my family doctor). However, until I finally insisted upon traveling 200 miles to consult a rheumatologist in September 1971, I had and was not given any true understanding of the disease and how to handle it. The public must be better informed about it and doctors, in general, better trained to handle it.

Our State needs treatment centers in more areas. It is difficult to travel to Milwaukee and/or Madison for care when one is crippled. Several more State programs, such as the one Mrs. Janice Pigg has at Columbia Hospital in Milwaukee, would be terrific. As a person with arthritis, I know that her personal approach to handling and living with the disease is the correct one.

Too many people I know with arthritis have given up and suffer needless pain and crippling for lack of a knowledge of it and lack of adequate treatment in the areas in which they live.

Please let Congress know how vital their help is to all of us. We don't have a glamorous killer disease--just one that insures much suffering.

ERICA HANSON AND LOREE DAVIES  
Madison, Wisconsin

October 31, 1974

As occupational therapists who are an integral part of an active team approach in managing the treatment of arthritis patients, we are writing to state our concerns as to where we feel the National Arthritis Commission could best focus its interests and funds.

The first area is public education. We find that too many of our patients are not getting the appropriate treatment early. They lack information on disease process, recommended treatment, and available resources. Advertising equates the seriousness of arthritis with a headache (e.g. aspirin commercials). Comments by the general public, such as "everyone gets a touch of arthritis as they get older," discourage individuals who have arthritis from seeking appropriate treatment. Even many family physicians tell their patients that there is "nothing that can be done for arthritis except take aspirin," and patients do not understand or follow a therapeutic salicylate regimen.

This leads to the second important need which is continuing education for physicians and allied health professionals. Current programs available are excellent, but more are needed. It is essential that physicians and health professionals possess a mutual understanding and respect for one another's roles, since arthritis is most effectively managed through a team approach.



Finally, but also of critical importance, is the need for continuing research. This needs no explanation--one need only look at the advances in new drugs for managing rheumatoid arthritis and those for completely controlling gout. Progress in this area must continue.

Thank you for your attention to these very critical issues.

MRS. HELEN L. HARLOFF  
Madison, Wisconsin

October 28, 1975

As a disabled arthritic, I am delighted to have this opportunity to speak out on one very important unmet need of arthritics and how I hope it would be met.

I am 56 years old and a relatively "new" arthritic. In fact, not too many years ago I worked for the Arthritis campaign as a telephone solicitor for volunteers. I was in good health and enjoying life to the fullest. And then it struck--osteoarthritis--as a result of an accident I had the misfortune to be in about eight years ago. I was a passenger on a city bus that was hit by a carelessly driven truck.

Since becoming an arthritic, I am appalled at the almost total lack of knowledge the majority of the people have in regard to arthritis, the arthritic, etc. How many, many times I have heard, "Well, you're lucky. You just have arthritis." And it is a sad commentary, but true--many, many arthritics' families think exactly that way. Most people simply do not understand what arthritis really is, how very painful it is, and that there is no cure for it.

I would sincerely hope that more could be done toward educating the public on arthritis with all its ramifications--pain, crippling, disability, no cure, etc. Arthritics know all these things, but the general public does not, and they surely should.

Couldn't some arthritis funds be spent on spot TV announcements, especially on well publicized programs; and not only during the arthritis campaign, but year-round? There are also many other ways to bring this before the public--radio, newspapers, speakers at service clubs, etc. I sincerely believe monies spent on educating the public on arthritis is almost as important as research, training, etc..

I also feel very strongly on who should appear before the Commission; namely, medical professionals and people with arthritis. I absolutely do not believe it is something elected officials, industry representatives, or labor representatives should do because it is not in their field and, I dare say, some of them are as ignorant about arthritis as Mr. John Q. Public.

I hope very much to be able to attend the hearing in Milwaukee, Monday, November 10, and I hope what I have written will be of some help in bringing more and better help to arthritics.

MARILYN HAUGEN  
Edwina, Minnesota

October 29, 1975

As a lay person, I wish to express my hope that Arthritis Act funds will provide for improved communications between the Arthritis Foundation and arthritis patients, between arthritics and their physician, and between the Arthritis Foundation and rheumatologists and general practitioners.

Our Minnesota programs stress education of both arthritics and physicians through public information forums; a statewide code-a-phone Message Center; newsletters to some 13,000 households; and distribution of pamphlets and brochures through the mail and at public displays, clinics, nursing homes, and professional associations. I would hope that the visibility made possible through greater participation on the part of both patients and physicians would stimulate a broader base of giving to the Foundation, as well.

We recognize the great need for research, as evidenced in the Minnesota Chapter's support of research programs at the University of Minnesota and the Mayo Clinic. Research is basic to the Arthritis Foundation's purpose, but arthritis sufferers need to know that they are recognized as a group and as individuals; that the Foundation cares for their well being; that information is available about their disease; that new information is provided to their physician for up-to-date treatment; and that proper medical care can prevent or minimize crippling.

Thank you for inviting my comments.

MARY GRACE HOARD  
Fond du Lac, Wisconsin

One of the unmet needs of an arthritis patient, such as myself, is the lack of communication to the public regarding this disease. More information should be given out so that the public can better understand the disease. I know that, as a victim of arthritis myself, my co-workers find it difficult to understand how you can feel just great one day and, all of a sudden, hardly be able to navigate. They find it hard to believe the pain that is actually suffered.

Another point I have often wondered about is--how much does the average family doctor know about this disease? Are special clinics held on arthritis, as they are held on many other diseases, to better help the doctor with his diagnosis? Many things I read tell me, "If you have arthritis, run, (if you can), don't walk to the nearest specialist." All right, this would be fine if there happened to be one fairly close. However, if your family doctor is treating you and keeping you going, how important is it to change? Would he not, in good faith, transfer you to a specialist if he felt he could not help you?

I feel that additional funds could be used to research facilities, to publicity, and better communication between patient and doctor. The more we can learn about this disease, the more we can be helped.

Milwaukee, Wisconsin

November 10, 1975

ROBERT E. HOUGH  
Greendale, Wisconsin

October 29, 1975

One of the basic problems connected with arthritis is the almost redundant misinformation as to treatment and/or supposed cures for the disease.

Priorities should be set where monies (Federal grants or foundations, etc) be used in a massive educational and information program to dispel the ignorance and witch's brew approach to an understanding of the disease. The public must be made to realize that this disease is both treatable and controllable, with strong emphasis on the latter, if proper treatment is sought out.

ALTHEA JAKUBOWSKI  
Oshkosh, Wisconsin

October 29, 1975

I am a 48-year-old housewife and inactive Registered Nurse who has had Rheumatoid Arthritis for 13 years, but I cannot remember what life was like before I got the disease. I feel as if I've always been fighting it.

The problems of fighting arthritis while keeping house and trying to raise three children are too lengthy to list in this letter. I do feel that one of my greatest frustrations has been a lack of instructions for exercises to prevent deformity. Many years ago, I believe the Wisconsin Arthritis Foundation put out a booklet explaining "Range of Motion" exercises, but it is almost impossible to obtain one now. I realize that doctors should refer their patients to a physical therapist who should teach them the exercises. but I feel in most cases this is not done. I feel we should have easy access to this information and be informed where to get additional therapy if needed.

When I asked my doctor to refer me to someone to help prevent more deformity to my right hand, he referred me to an orthopedic surgeon who recommended surgery. We hear publicity every day about surgery to rejuvenate arthritic joints, and this is a tremendous achievement, but not enough is being done to prevent deformity.

I live in a city of 50,000 people that might possibly benefit by some sort of "Hot Line" arrangement for arthritics. Also, the last few years I have had short severe attacks of arthritis, I feel are due to the menopause, but have received no help whatsoever from either my gynecologist or medical doctor. I'm certain money spent to train more rheumatologists is the answer to this problem. We do not have one in this vicinity.

Of course the greatest need of all arthritics is for research to find the cause and cure of this disease. I feel the knowledge we have from past research is totally inadequate.

I am very interested in the National Arthritic Commission's work and hopefully will be attending the meeting in Milwaukee November 10th. •695



ELEANOR C. JORGENSEN, R.P.T.  
West Allis, Wisconsin

November 5, 1975

Too many persons with arthritis do not see their physicians soon enough when symptoms appear. They self-diagnose and self-medicate with patent or quack remedies far too long before seeking medical care. This points up a great need for education of the public about arthritis. The need being recognized, there remains the problem of how to do this. You can't beat the mass media, television especially, for reaching the public. The recent hour-long presentations dealing with cancer and with the respiratory problems seem to have been excellently done and made an impression on the viewers. I think money spent on this kind of an educational program for the public about arthritis would be very effective.

I feel there is apathy on the part of many physicians when it comes to treating the person with arthritis. Many physicians are unaware of all that can be done for the arthritic via carefully monitored drug therapy; physical and occupational therapy to relieve pain, to maintain as much strength and range of motion as possible, to minimize or prevent deformities, and to teach the person joint protection and energy saving techniques; appropriate surgical procedures at the optimum time for joints severely damaged by degenerative joint disease or to prevent the rheumatoid arthritis process from damaging joints and causing contractures and deformities; to correct deformities which have occurred. I am afraid too many physicians slough off the person with arthritis with palliative therapy and the counseling that, "You have arthritis. Unfortunately nothing can be done about it. It can't be cured. Take aspirin as you need it for relief."

Because there are not enough centers offering a comprehensive, multi-disciplinary treatment approach to the treatment of arthritis, many physicians do not know of their existence or what is being done at such a center. So the arthritis person's family physician in many instances is not making a referral. If a hospital with a comprehensive arthritis program is 200 to 300 miles from a victim of a disease, the distance is too great and he probably never will be referred there. So, there is a double-barreled need for education of physicians of what can be done nowadays for the different kinds of arthritic conditions, where it can be done, and method of referring patients.

In my work as an allied health professional I have seen too many persons who have not had the best possible management of their arthritis. They have followed their own inclinations and are very sad cases indeed, with irreparable damage to multiple joints causing gross deformities. They are found wheelchair bound or ambulating so poorly that it isn't practical, unable to carry out the basic activities of daily living. So much of this could be prevented with early intervention by medical and allied health specialists in treating the person with arthritis. There is need to make persons knowledgeable about arthritis, what medical help is available to them, and how to get into the system.

Milwaukee, Wisconsin

November 10, 1975

JOHN KANAROWSKI  
Germantown, Wisconsin

I write not only for myself but for 2 people within 10 miles who cannot write! There are others, I am sure, in this area who also suffer from arthritis. We need a better answer to what to do when the pain keeps us awake then, and I quote the arthritic handbook: "Count the floor tile, the spots on the wall. If that doesn't help go in the bathroom and bawl your head off."

What we need is something like the AA has. Small groups who meet and discuss their problems in the hope it will help others. I am an AA member. If it was not for them I would be dead as booze would have been my answer to the damned constant pain. Speakers could be brought in, advertise it in outlying areas and open it up to the public when there is an open meeting.

It may be impossible for us to come way downtown in Milwaukee. That's no damn place for a meeting. No parking, too much traffic, and too far to go. I'll do my best to attend. Meanwhile another letter -- "this one" adds to the pile of Government redtape--of paper work. Loss of time so more people can be added to the list.

God help you in your work as he has helped me the past 3 years. It didn't take him that long to make the world as it has to get this Commission going.

MAE KAPPELMAN  
Milwaukee, Wisconsin

October 1975

I am seventy years old and have rheumatoid and osteo arthritis. It is a very tiring, painful, depressing, and frustrating disease.

When I do anything different or more than usual I have trouble after. I notice other people doing things that I could do before, and I get very frustrated. People that don't have the disease don't understand it and wonder why you don't do more things. Have trouble with my feet and can just wear clunky shoes--never feel dressed up.

I think the unmet need is to find the cause. Also, medication with less side effects. The Government doesn't spend the money they should, as there are so many people afflicted with this painful disease. They could curtail some of their other expenditures.

I am happy to have this opportunity to express how I feel.

LORRAINE KLAMER  
Racine, Wisconsin

October 23, 1975

We are deeply grateful to Congress and President Ford for signing into law the National Arthritis Act. Eleven years of my life were spent as a registered nurse doing general duty, head nursing, and supervisory work in two hospitals in Michigan. Many of my patients were those who had rheumatoid arthritis and couldn't do anything for themselves. I thought, "My, what an awful disease."

It was only when I myself became a victim of R.A., eighteen years ago, that I realized how little I had been taught or knew about the disease. At that time our children were two months and twenty-two months old. My husband was a graduate student, and we were living in Lansing, Michigan.

When our local MD said he suspected R.A. I couldn't believe it. He prescribed aspirin--not telling me that it had to be taken regularly, whether or not I had pain, nor was I told anything about its anti-inflammatory properties (this was in 1958). My opinion of aspirin was very low, but I did take it arising in the morning and always let the warm water run over my hands until my fingers and wrists would loosen up enough so that I could turn on the stove burner, prepare the bottle, feed babies, and get breakfast. Diaper pins I managed with my teeth. I couldn't afford to be sick, and there were no grandmas or relatives around to help out--so of course it didn't get better.

Three years later we moved to Ann Arbor. The arthritis wasn't quiet, but it wasn't bad. I had a minor auto accident and broke out in a rash. To treat the rash I was given tranquilizers, antihistamine, and Medrol. (This was done by a new family doctor who knew I had R.A.) When I came off the Medrol, there was an acute flare-up of arthritis.

Now I realized I had to find a doctor who knew more about my situation and called an endocrinologist who was a fellow church member. He had his friend, Dr. Mikklan, call me the same day, and that is the first time I knew that there were such doctors as rheumatologists.

I was admitted to the University of Michigan Hospital the next day....and for the first time really learned how to take care of myself and live with my disease. From 1963 to 1965 we lived in Europe and then came to Racine, Wisconsin. In Racine I called a member of the Arthritis Foundation and was referred to a local internist.

I was under his care for five years but realized my condition was worsening and he didn't know what to do about it. When I asked for a specialist, he didn't know where to send me. The local library and public health departments were no help either.

I'm a graduate of Blodgett School of Nursing in Grand Rapids, Michigan, and knew Dr. A. B. Swanson, so called him for advice. (He later put silastic implants in my wrist, hands, and big toe.) Through him I discovered Dr. Bernhard, a rheumatologist, right here in Milwaukee. He is such an excellent physician for my disease (I spent some angry days



wondering why I had to go through such a frustrating search in order to get the help I needed when it was so near by).

In my experience there is no comparison between the way the family doctor or internist handles the problem of arthritis and the way the rheumatologist does it.

Both rheumatologists I have had showed their special knowledge and understanding of the disease in the way they performed the physical examination (especially the joint exams) offering hope even when the patient feels all is hopeless, and when inquiring about rest, medications, and exercises, not saying, "do you?" but "when and how much." Being a consistently good patient takes a lot of self-discipline, and these specialists realize how much encouragement we need.

During my hospital stays at Columbia in Milwaukee I have gotten to know the rest of the arthritis team and these wonderful supportive people make me feel that they really care about my future as they go about their tasks of teaching me how to live and function better in my environment in spite of my disease.

I have attended seminars put on by the Arthritis Foundation for doctors and allied health professionals in other cities and also educational meetings which were open to the public. These are excellent and I wish more people could attend.

Living with arthritis is a daily struggle. Constant pain, fatigue, and gradual loss of function is very humiliating and discouraging. Cancer and heart disease receive more attention because they are dramatic killers. On the other hand, the pain and crippling of arthritis go on year after year while the patient becomes more of a burden to himself, his family, and society. Often he would prefer death to the condition he finds himself in.

Yet there is always hope that a new drug or treatment will make life easier. I am on many drugs, the newest of which is Imuron. I got into and out of a bathtub by myself for the first time in 5 years. Yesterday I drove the car for the first time in 2 1/2 years. Two years ago I thought my life was headed only downhill. Now I have hopes and plans for the future.

How should you spend the money?

- (1) Train more rheumatologists.
- (2) Every nursing school should be offered up-to-date information in this field, and there should be more nurse specialists in this area.
- (3) Our community (Racine) is very short of physicians of all kinds. It seems to me that allied health personnel could help to close the medical care gap in an area like this.

- (4) Communicate with public libraries to see that they are carrying good, up-to-date reference materials on this subject. (Ours was not, but did respond when I sent them a list suggested by the Arthritis Foundation.
- (5) The local library had no provisions for books for shut-ins, but agreed to send them cassettes (ordinarily used for the blind) when asked to do so.
- (6) Inform the public on how to choose a good doctor and how to judge whether one is receiving good medical care or not. Use TV specials, Readers' Digest, Good Housekeeping, etc.
- (7) Teach people how to recognize the quack or his devices--again through public media.
- (8) Make health insurance available to the arthritic who can't qualify for any other.
- (9) When a patient is taking a drug which is basically experimental, all the medical costs and lab work associated with it should be covered by a research grant.
- (10) Form local groups of arthritics who can encourage, support, visit, or call one another and have good, helpful literature available to lend or give out.
- (11) Educate, educate, educate--doctors, nurses, physical therapists, occupational therapists, and especially patients. Also, I want my friends, relatives, and neighbors to be so well informed that they will never recommend another diet or quack device to me.

My hairdresser gets to hear all about her patrons' problems, aches, and pains. A great bit of misinformation and old wives tales are passed around there. Arthritis is a main topic since it is so common. This hairdresser would be more than happy to have some helpful and accurate information for interested customers to read while under the dryer. I will supply her. What about the others?

Thank you for allowing me to express myself.

CAROL KRING  
Sturgeon Bay, Wisconsin

October 28, 1975

I first want to thank you and all others for your dedication to this cause and wish you the best of luck!

I have many friends and acquaintances also afflicted with this terrible disease. Of course they are all in varied degrees, but all very painful. I have rheumatoid arthritis, and this is my eighth year. I've had to give up teaching, most housework, hunting, golfing, and other outdoor things I love to do. Thank goodness I like arts and crafts to take care of some of my depressions. I'm very thankful, I worked many

years before so I'm able to collect disability insurance, which takes a big load of my mind and my family. Without it we could not make ends meet.

My disease was not diagnosed until it became serious. I had none of the symptoms they claim go with the disease. I entered the hospital and was given shots and drugs to calm it down. After trying several drugs and finding one that that seemed to help some, I went back to work; but an aide was hired to do most of my walking. It was still very very hard on me but I continued for five years as we needed the salary to survive. To try and find another job is impossible because I never know when my fingers, wrists, arms, and etc. would be sore.

Whenever I'd go to the doctor when I was really bad, all he could say was, "There is nothing we can do for it." For the last two and a half years, I've been going to Marshfield Clinic. I was taken off the drugs and put on aspirin, examined and range of motion measured, and some methods of treatment given to me. Five or six weeks ago I entered the hospital down there because my knees were so bad I needed crutches. I was there for two weeks. I was given steam heat baths twice a day, worked my limbs to their fullest range of motion, and lifting weights. I also had occupational therapy where I was given hints on how to do things different to prevent further damage to joints; and several exercises to do twice everyday. I was also given cortisone in my knees, and I was started on gold shots and was told to stay off my feet till Christmas, at least.

I know now all exercises and the reasons for doing them, but never to overdo. I'm up and walking from room to room, and doing so somewhat normal; but my wrists and arms have bothered again. Hopefully the gold shots will take over soon. If this goes against me I have no idea what they'll be able to do for me, because I've tried all drugs made especially for arthritis and they don't agree with me.

I know there is an arthritis fund drive, but it has never reached this area. I hear about the organization once in a while on TV and most people we talk to know nothing of any of this.

I'd like to see information gotten out to all the public, not just arthritic people. We need to educate people on its symptoms, like we do cancer, to catch it in early stages. We need doctors better informed of the disease and new drugs and treatment of it. We need in this area a treatment center. People should be informed as who to see for assistance and how to obtain it. And any additional funds that you might obtain for this disease could go for all the above, especially treatment centers or home care perhaps, and above all research for a cure. It would take care of so much misery and suffering and put people back to productive, happy individuals.



Milwaukee, Wisconsin

November 10, 1975

IRENE MEIKLE  
Dodgeville, Wisconsin

October 28, 1975

I have arthritis--osteoarthritis--and have had one total hip replacement. I feel a great need for arthritics is learning about the disease. Many of us cannot afford to go to rheumatologists regularly. If informed persons could speak to groups of older people at senior centers, it would be a great help.

Last week I talked to a senior citizens group about the Commission's hearing November 10 and the need for letters to be sent. So far, one person told me she has written, there was one phone call, and many expressed their interest.

I am also trying to get people to become members of the WAF.

MRS. W. P. MINOR  
Mequon, Wisconsin

October 20, 1975

I received your letter asking for information for the National Commission on Arthritis.

I would like more information. I want to know what I can do to help me walk. I have had trouble since 1945 (about). It would come and go. The last 5 years I have used a cane once in a while for balance. At times, I thought if someone would bump me I would fall. Now the last year it is getting bad. I lose my balance--my right knee freezes at times. I always have pains in my legs and feet, my arms, and at times all over my body. I can walk through the Sentry with a car. That is about as far as I can, at times I can't.

The doctors say I have polyosteoarthritis. They can do nothing for me. Just take two to four aspirin four times a day. I always walked a lot.

Can I do more to help myself to walk? I don't sit much, as I have too much to do.

MARY MORITZ  
Milwaukee, Wisconsin

October 30, 1975

In the past two years I have been involved as an instructor in a series of self-help classes designed to help the arthritic person learn more about his disease and how to best cope with it. Many of the participants in these classes had very little knowledge about their disease and found the classes very helpful. I feel this type of community program was most beneficial, and programs of this type should be continued.

Another factor that has become very evident to me after working with these arthritics and working with arthritics in a physical medicine department of a large general hospital is the lack of physicians who are

Milwaukee, Wisconsin

November 10, 1975

knowledgeable in the area of rheumatology and how to treat people with a chronic disability.

I feel it would be very worthwhile if educational programs and funding would be directed towards interesting more physicians in this area. Funding for research is another area that I feel should be given much consideration.

FRANK JAMES MOZE  
Milwaukee, Wisconsin

October 27, 1975

May I suggest that in addition to research the most fundamental and immediate need for people plagued with arthritis is education.

It has been by related experience as an arthritic the past 27 years that millions of dollars are being spent by the public for pain relief or supposed cure that has as its basis, directly or indirectly, "out and out right fraud," and is further aided by well meaning friends with stories suggesting what to do, what to buy, and where to go.

I trust in my small way I can cast some light and convey a more positive approach (education) to a very maligned disease.

MRS. H. MULLARKY  
Milwaukee, Wisconsin

October 21, 1975

I am very interested in new things for arthritis. I have had it for over 10 years. I am always listening for new ways to live with it. I belong to a group that took the sessions at St. Lukes Hospital. We meet once a month to share new ideas about the disease.

Thank you for sharing and helping.

MRS. LORRAINE NELSON  
Milwaukee, Wisconsin

More doctors should be made aware of the fact that people need help in coping with arthritis. More money should be available to younger doctors, nurses, and therapists so they can go into the field of rheumatology.

If I had found the right doctor about 20 years ago, I am sure I wouldn't be in so much pain that I suffer ever day. And I wouldn't have been disabled in my forties.

I have gone to about 10 different doctors in that many years. All they sad was, "So you have arthritis. There's no cure." But there is help, when we know where to seek it.

I read a notice about self-help classes in the paper and was fortunate to be able to attend. From there I found out about the Wisconsin

Milwaukee, Wisconsin

November 10, 1975

Arthritis Foundation and became an active volunteer. Though I am disabled, the Foundation knows my limits and gives me suitable jobs. They realize I must rest every hour or two.

There also should be more information out to people, so they can be aware of what the Arthritis Foundation can do for them. This is also where the needs for more funds should be made available.

I now wear a soft neck collar and back brace because my fourth, fifth, and sixth vertebrae are degenerated. This keeps me from using my arms to some degree.

I am glad to be able to express my thoughts to you.

MINNA OHLSEN  
Milwaukee, Wisconsin

October 29, 1975

I am sorry to state that I am unable to attend the meeting, due to my arthritic condition. Will make this brief.

- (1) I think more research is necessary. So much is done for cancer and so little for arthritis.
- (2) We should get the message across to industry and union representatives, because so many man-hours are lost on account of this dreaded disease.
- (3) Write letters to our elected officials in Washington.

Due to my hands, I am unable to write as much as I would like.

DOUGLAS PETERSON  
Waukesha, Wisconsin

I think there is a need for more knowledge for arthritis victims of all the new treatments. Tell people to try different things, maybe one cure will work for them. I think some funds should be spent testing diet for pain relief. I understand there are special diets for arthritis victims, but these are not easy to get hold of.

MRS. EVELYN POHL  
Greendale, Wisconsin

November 31, 1975

First of all, let me say that this hearing being held here in Milwaukee is certainly the beginning of an effort to make everyone more aware of the real need that something be done for victims of arthritis. Just because the disease is not always confining or completely disabling to the patient as shown, little concern is given to the patient.



November 10, 1975

A. Doctors tend to ignore complaints of arthritic pain. Their stock answer is that little can be done for it.

B. Not enough specialists that want to deal with arthritis treatment.

C. Loss of work time must be great due to arthritic pain, but it just doesn't seem to be recognized as the large factor it is. Industry should help finance some research into early treatment.

D. Information should be available to everyone as to where to go for treatment and what results can be expected.

I'm sure there are many other things that should be done to help the arthritic patient, and I for one sure hope that time comes soon.

The very best success in this venture.

SYLVIA E. SCHMIDT  
Campbellsport, Wisconsin

October 24, 1975

Before I became a victim of rheumatoid arthritis, the disease was just a pain in somebody else's joint. It was not until I developed it that I realized that anyone can get rheumatoid arthritis. Fortunately, I was able to get good medical care, but in spite of it, I have become disabled to the point where I am unable to carry on the duties expected of me as a classroom teacher.

During the 10 years in which I have had the disease, I have kept on hoping that the cause and cure would be found. If it is the lack of money which makes it impossible to carry on the necessary research, I would hope that somehow we could educate the public to the need for funds. Yes, there are many other drives for cancer, heart, lung, etc., and who is to say they are not equally important. This thought has occurred to me many times. If there are 17,000,000 people who suffer from arthritis, would it not be wonderful if each one could contribute \$1.00 annually to the cause of research and education. I know this is an unrealistic goal, but perhaps those of use who can, need to do more.

The W. A. F., through its books and other materials helped me to understand the nature of the illness, the need for good care, and relieved me of some of the fears.

The Milwaukee Journal articles were also excellent. Educating the public is important. Too many people still think of arthritis as old fashioned rheumatism which strikes the elderly and with which one has to live.

For me, the most difficult part of being disabled is coping with the lack of understanding on the part of many people.

Good care, understanding, and finally cause and cure are all needed. At 61 I am still waiting for a miracle.

CAROL SEAMANS  
Reedsburg, Wisconsin

October 1975

Having had rheumatoid arthritis for 30 years, I feel the following most urgent unmet needs are important:

- (1) Research. More funds should be available to find the cause and cure of the crippling effects of arthritis.
- (2) Local physicians should have more education and knowledge in diagnosing and treating the arthritic patient. (I had suffered nearly 20 years before getting professional treatment such as medication, exercise therapy, rest, and other useful information about this chronic disease.)
- (3) More information for the general public is needed by medical professionals or health nurses to give lectures to generate public concern for the arthritis cause. And also, home care programs to help the arthritic in rehabilitation with such things as self-help devices to help carry on everyday activities.

I also know that no one can understand the pain, fatigue, and depression of this disease and also the mental, physical, and economic damage to the sufferers' family, like another victim of the same crippling arthritis.

JOANNA H. SPIRO AND MARY CLAIRE HAYDEN  
Milwaukee, Wisconsin

October 29, 1975

Following is the statement that we would like to submit to the National Commission on Arthritis:

Today, the patient and his family are searching to find ways to help themselves by learning to adjust to and manage the chronic disease, rheumatoid arthritis. But, what of the professional staff? Are we prepared to develop educational programs that speak to these needs? All too frequently, in health agencies, the multidisciplinary team is in a hurry to impart facts before the patient and family are ready to hear them. What of the family? Are they involved in our teaching programs? When we impose ideas upon people, we train them. If we merely impart factual information, we train them. When we create an atmosphere in which people are free to explore ideas in dialogue and through interaction with other people, we educate them. If we share factual information, the content which is relevant to the patient and family personally and it is given in an atmosphere which encourages active participation by patient and family, we educate them.

Today's professional health team must be prepared to develop educational programs for the rheumatoid patient and his family. In the past, we have developed training programs because it seemed easier, quicker, and cheaper. Today we need to urgently look to the educator to help us develop programs using adult educational principles and methods. The first step in such a program involves educating the staff.

We need to develop a city-wide continuing adult educational program which is designed to educate multidisciplinary health professionals. The techniques would involve listening and communication skills by means of small group process within a clinical setting and/or university setting. Professionals throughout the community would be invited to take part in a learning experience that they could then take back to their respective institutions. In turn, it is hoped they will develop in-service programs using these same educational principles.

The continuing education program we wish to develop is a dynamic, exciting program utilizing expertise in the health and educational fields. It is imperative that professionals recognize their need to know and also how to correctly present educational programs for the patient and family. The thrust of such a program would be a non-authoritarian, truly educational process which would include the patient and his family in an atmosphere conducive to learning. It would emphasize individual needs and a willingness to accept the patient and his family where they are and continue from there.

It is our belief that no program can be effective without the willingness on the part of all participants (professional and client) to understand the difference between laying down rules and true education. It has been our experience that rules are broken, but that participatory education is meaningful, long-lasting and a valid approach to this disease.

JOHN G. STENGER  
Milwaukee, Wisconsin

October 29, 1975

A victim of arthritis, I am responding to your request. I am writing to express some of my thoughts regarding my views (limited as they are) as to what can be done to not only help arrest or cure this terrible, crippling disease.

First of all, I am suffering from osteo or degenerative arthritis, and it has primarily and seriously affected my right hip and right knee. During the past few weeks the pain in both has gotten exceedingly worse. Hobbling along on one crutch, have been obliged to stop driving my car. Indocin and other pain medication, such as darvon 65mg. plain capsules, are no longer effective to kill the pain.

My doctor has set up an appointment for an office examination by a surgeon in order to determine if a new hip replacement is prescribed. My appointment is over a month away--December 3, 1975. One of my thoughts is to stress in the minds of potential sufferers and the public in general, to have regular examinations to prevent getting this disease, then to arrest and/or effect a permanent cure.

Perhaps the general public does not realize the toll that this disease is taking. The medical association, the Government, and other organizations should impress the need for intelligent information to bring it uppermost in the minds of us. Then those who are victims of a mild



Milwaukee, Wisconsin

November 10, 1975

form in the early stages should be alerted as to what to do to eradicate this disease.

I believe that proper, correct therapy should be stressed. Importantly also, information should be publicized to wipe out the charlatans which are in such great numbers with fake claims and fake cures.

I am a victim who, until recently, has paid very little attention to arthritis and probably would have treated it very lightly, until the disease hit me so severely. Thank you for the good work which you are already doing in behalf of all types of arthritic sufferers and victims.

JOHN J. TIVANOVAC  
West Allis, Wisconsin

October 20, 1975

I would like to present the following views to your Commission for consideration at the Milwaukee public hearing on November 10, 1975, or to be considered during your later deliberations:

- (1) Information: There seems to be little public information (in newspapers, magazines, or in the local Arthritis Foundation newsletters) of just what research is being undertaken with Federal or State funds to find new methods of at least controlling pain and preventing deterioration of joints and limbs. What avenues are being explored?--New drugs, new exercises, physical/manipulative therapy, diet? Whether such research is definitive or not, I'd like more information on specific avenues of research. Exactly what funds are being spent for.
- (2) What is being done to coordinate research and treatment methods in this country with that undertaken in other countries? Perhaps we can learn much from other countries and thus give more help to arthritics.
- (3) Specifically, what little things have other arthritics discovered through their own experience that can at least alleviate pain and make an arthritic more comfortable and able to lead a useful and somewhat normal life?

MRS. SANDY WEISS  
East Troy, Wisconsin

October 21, 1975

I am a thirty-year-old mother of three very active daughters and a recent divorcee. I have psoriasis rheumatoid arthritis in every joint as well as in my spine.

What is badly needed is a broad public education of what this disease is: the ups and downs of it; the emotional stress in the patient; the great variance in pain and stiffness levels (one day, maybe you are fine, but the next day you are in bed because the pain and swelling is so bad!).

Milwaukee, Wisconsin

November 10, 1975

I'd really like to see a program where we (the patients) can get or borrow at low interest the money necessary to get something we really need. I'm now a college student at Whitewater and must type book reports and some other technical papers. I only own a cheap manual typewriter, a portable, which I have a lot of trouble with; the keyboard is laid out wrong for arthritis, plus the pressure necessary to make it type is excessive. I do a lot of letter writing of a legal nature where I need carbon copies. Therefore, I would really appreciate a standard size electric typewriter along with a stand. It's becoming imperative that I get one because my quality of work for class is suffering; it looks sloppy.

I feel our doctors should be more honest with us. I know what is going on with my spine, but the doctor is afraid or unable to talk about it with me. I'd appreciate more candidness, even if he may be only guessing, because I could be better prepared for what the future may bring. It is frightening to suddenly find you are almost paralyzed because of this spinal arthritis! It would be comforting to know there is household help available so the children will be cared for by a competent adult. Many of us women are in the same situation (whether married or divorced), worrying about our children, which makes these bouts last longer. Someone has to help us!!!!

Thank you for caring and for trying to help.

MRS. ANNETTE J. WIEGAND  
Sheboygan, Wisconsin

October 25, 1975

I am age 34 and have had rheumatoid arthritis for 15 years. My biggest difficulty is walking stairs, and I wish more buildings had ramps or elevators.

I now go to Madison University Hospital to see Dr. Mark Muller, and I feel I finally am getting good management.

It was nearly impossible to find a doctor in Sheboygan who wanted to treat me. The advice I received from one of our better known MD's was, "There is nothing you can do for arthritis!"

Therefore, joint damage was done as I waited, finally taking 4-5 mg cortisone tablets a day!

I think programs such as the self-help classes are excellent!

I would hope, of course, that research would make advances. Also, that we would know more of what researchers are doing and learning.

Milwaukee, Wisconsin

November 10, 1975

MRS. ANNETTE J. WIEGARD  
Sheboygan, Wisconsin

October 29, 1975

The educational aspect of the Rheumatic Disease Center which I attend is most important. We learn to be self-sufficient as long as we are able, giving us renewed hope and preventing us from being lifetime, bed-ridden patients in an arthritic ward of some hospital.

The regular physician hasn't the time to begin to devote to us arthritics. We need these specialized, dedicated people of these rheumatic centers to educate us in an involved program, including medicine, proper rest, physical and occupational therapy. Only they understand our problems and are capable of setting up a proper program for our individual needs. This should be available to every arthritic.

JEAN F. FULLER  
Oshkosh, Wisconsin

October 30, 1975

Good morning, thank you for asking my opinion!!

My need, as one with this disease, is "financial." I need help with my housework. I need treatment. Each day is a struggle. I have found activity, then rest, activity again, helps me. But I can't find enough hours in a day to accomplish all that must be done. My husband, children, dog, house, all need me. I am very important to my family. Unfortunately, my family is not educated about the illness I am trying to cope with. Until you experience R. Arthritis, no one can understand.

We need medical clinics for this disease, with lower fees for low-income families, and volunteers to work in them, which would cut cost of upkeep!! I am ignorant myself of this disease. Because my family physician is!! The cervical is destroyed, deterioration of the spine. Headache and ear on right side of head. Clinics, education of M.D.'s, money, for lower income patients like me. I could write a book on what our needs are, but--best mail this now!!

Perhaps another time I can attend one of your meetings. Just knowing I am not alone, and someone cares, gives me a lift.

WINIFRED KUNZE  
Elm Grove, Wisconsin

October 1975

I hope this is something that you wanted. It's anyway my interpretation of your request.

After my husband's death I decided to go back to school to do advanced college work in a new field that would certify me as a remedial reading teacher in the public schools. I was amazed after only three months of very satisfying teaching that I became ill; I had great pain in my feet and was almost incapable of putting on a coat alone. When I came home at the end of the school day, I flung myself on the sofa, exhausted. My illness was diagnosed as rheumatoid arthritis.



After only one and three-fourths years of rewarding teaching, I was forced to give up teaching permanently. I went to Mayo Clinic for a month's bed rest and treatment, followed when I returned to my home town by their supervised home care. Mayo would not release me until I had made arrangements to live with my sister. It was six months before I could go to my own home and be on my own.

Except for times when I am physically in an active state of the disease, I find myself perplexed with the disease. Psychologically I am plagued with the feeling that I could be more active, that I am giving in to living less than I need to, that I should be able to be a more active participant.

I think, therefore, that it might be helpful to talk with other "rheumatoids" to see if others feel this way. I have been considering going to a Chronic Discussion Group, I believe it's called, which meets weekly at a local hospital, organized by a woman who has rheumatoid arthritis. She apparently is not prevented or deterred from creative initiative.

Part of my reduction in activities lies in the fact that I often do not feel well. I ask arthritis professionals if this general debility is characteristic of the disease--or is it from the drugs I am taking? When the disease is active, I often feel as if I have the flu--ringing in the ears, a sudden gnawing, empty feeling in the stomach, a feeling of "turbulent acceleration" as if within my body a war is going on. This "turbulent acceleration" in other years I would have associated with an infection and fever. What puzzles me is that other "rheumatoids" I have asked deny having these feelings of ill health. And so I wonder about me. Is it the disease or is it me? Or is it the drugs?

I have gone through gold treatments unsuccessfully--have used Cuprimine (Penicillimine) successfully for over a year and a half, ending a bit better than two months ago, as an accumulating tiredness developed. I became winded and again I experienced the "turbulent acceleration"--this time increased. My eyes bothered me. My lids became swollen. It was discovered that I had developed 4-6 extra heart beats per minute. I wonder, were these characteristics the effect of the drug, or the effect of rheumatoid disease?

The very fact of not knowing the answer to my unequal physical feelings bothers me. What is characteristic of the disease? I know this is a variable disease; yet I am hoping the National Arthritis Commission and the National Foundation of Arthritis can prepare, through literature, an honest appraisal of what to expect of the disease.

My point is I have to know what is happening to me to accept it and live with it. Knowledge helps.

Milwaukee, Wisconsin

November 10, 1975

WINIFRED KUNZE  
Elm Grove, Wisconsin

November 3, 1975

My sister-in-law, who has "lupus," was informed by her doctor in Madison, that all her medicine pertaining to her disease would be paid for. (By whom, I don't know; Government or experiment.) I recalled discussions in the newspaper about the future possibility of medicine for arthritis being paid for by the Government. (I have heard nothing about this within the last two years.)

I therefore inquired if I too might receive medical expense payments and was informed at the May Annual Meeting in Milwaukee that Medicare for arthritis would not qualify for payments.

The cost of medicine for arthritis over a lifetime could be economically draining. I would suggest consideration of this possibility by the National Commission on Arthritis.

MRS. LORRAINE H. KUOLT  
West Allis, Wisconsin

October 28, 1975

The purpose of my statement is to make you and the Federal Government aware of the inequities of the present Medicare System as it applies to people with permanent disabilities such as arthritis.

In July of 1973 I entered the Medicare program due to a disability of rheumatoid arthritis and a chronic bronchial condition at age 56.

An arthritic requires constant and regular therapy treatments, such as heat treatments, parafin therapy, Hubbard bath treatments, and exercises. This therapy was supplied on an outpatient basis in a hospital, under the direct supervision and control of a physiatrist.

The purpose of my therapy was to prevent the fusing and further deterioration of my joints, which would finally lead to total confinement in a wheelchair. I have been receiving outpatient physical therapy twice a week since July of 1968.

In November of 1974 I was advised by Medicare that there was no improvement in my physical condition due to the therapy I had received within the one year's time limit imposed. Therefore, they decided that Medicare could no longer cover any further services I would receive on an outpatient basis.

The Medicare program, as I understand it, was written to cover persons 65 years old and older. In spite of these rules as written, the program has added a new group of disabled people to an existing program without providing a new set of rules to apply to them exclusively.

By limiting the medical benefits to the disabled, the program is defeating the original purpose of the plan and discriminating against

those who cannot recover in the same manner and at the same speed as others with different afflictions.

Long-term chronic disability requires therapy that does not restrict the amount of medical attention nor the time the individual receives it.

Many people are unfortunate in encountering a rejection by the Medicare Administration because there is only a limited amount of improvement that can be obtained in treatment. After treatment, a peak is reached, and the most that can be hoped for is a temporary remission. From then on it is just a matter of preventing a new flare-up.

I feel that the Arthritis Foundation and the hearing should bring out the fact that people who have a disability should be able to continue treatment and not be rejected because there is no visible improvement in the person's condition within a limited period of time.

A person on kidney dialysis is not rejected when their condition is stabilized; why should an arthritic?

DOROTHY F. SOLBERG  
Wauwatosa, Wisconsin

October 22, 1975

I am writing in reply to your letter, October 17th, asking for statements reflecting what I feel is my most urgent unmet need as a person who has arthritis. It is an obvious fact that those of us who are afflicted are primarily concerned with a cure or at least more adequate drugs to offer relief. Our hope is in continued research.

Beside this, I am particularly concerned about the inavailability of hospitalization insurance. When my husband died a year ago, he was a partner in a very small firm that, at that time, did not qualify for Blue Cross, Blue Shield or other group insurance. Because of my ailment, I cannot work full time and so I am not eligible for group insurance myself. I was able to get a small hospitalization policy with a rider excluding any hospitalization due to my arthritis. I have been advised that if I should fall and break my back, the company could state that the fall was due to weakness in the ankles caused by arthritis and refuse to settle the claim.

At present, I have some large rheumatoid nodules on my arms and elbows that would require surgery. I am 49 years old with one dependent son still living at home. Our Social Security payments don't allow for such luxuries as hospitalization and operations uncovered by insurance.

Is there any possibility that an insurance "pool" could be formed by major insurance companies that could provide "uninsurables" with some hospitalization insurance, much like the auto insurance "pools" for poor risks? If not, maybe our only hope is that the Federal Government will get around to establishing a health program that would fill our needs.

Thank you for your concern and for your efforts on our behalf.



MRS. JACK SUNDE  
River Falls, Wisconsin

October 28, 1975

Yes, I am a victim of arthritis. I have had it since I was 16 years old. And it is a disease that gets worse instead of better.

I am 57 years old and have been able to hold down an eight-hour-day job. But some days it was very difficult to do it. Now I am just working three hours a day as I am getting weaker. The pain is terrible some days. I wish there was some place in the community that a person who has arthritis could get a job, which would be available for handicapped people. I am not crippled yet, but I just pray every day that I am not in a wheelchair. We have arthritis in my family. There are five in my family who have had to quit working, and you can't get Social Security until you are in a wheelchair. Where can a person turn for help?

MRS. W. WICKERT

October 22, 1975

Just hurry and find a cure somehow or some way with the Lord's help too. It is too expensive to have especially when you have tough times as we financially.

SUSAN J. CORNWELL  
Hales Corner, Wisconsin

October 17, 1975

I am eager for the National Arthritis Commission to learn all that it can about the unmet needs of arthritics in the Milwaukee County area. I am responding as philanthropic chairman of Alpha Omicron Pi--Milwaukee Alumnae Chapter. I have enclosed our pamphlet, which explains what AOPi has done and will continue to do as a community social service organization.

The Milwaukee Alumnae Chapter cooperates fully with the Wisconsin Arthritis Foundation and its programs. I serve on its board of directors in order to fully understand its services and programs and to facilitate our mutual efforts.

Some of the special needs in this area are as follows: (1) further development of a multi-media public awareness program, (2) expansion of self-help classes, (3) adaptation of public facilities for greater physical convenience of arthritics, including lowered telephone booths, ramps, grip bars in washrooms and baths, and (4) development of a broadened awareness program for physicians, nurses, therapists, allied health persons, teachers, etc. . . .who diagnose, refer, or otherwise deal with arthritics.

I am confident you will realize that there are great possibilities for programs and services on a local level. Governmental support is vital in order for it to succeed.

Milwaukee, Wisconsin

November 10, 1975

CHARLES E. DYKEY  
Chicago, Illinois

October 10, 1975

As a lay member of the Board of the Chicago Chapter of the Arthritis Foundation, I have been greatly impressed with the fine progress of this regional activity. I have been particularly impressed with the work of the clinics, several of which I have visited.

We are aware, in our region, of the need for funds to substantially expand arthritis research, training, public education, and treatment facilities. We understand that primary attention is being given to the development, modernization and operation of comprehensive centers. I enthusiastically endorse this posture of your Commission.

I urge your Commission to recommend positive steps by both the Administration and Congress in the implementation of the proposed national attack on arthritis.

MARY GRISAR  
Milwaukee, Wisconsin

October 26, 1975

I received a letter from Mrs. Janice Pigg, R.N., who is Dr. Gerson Bernard's consultant in Milwaukee informing me of the public hearing to be held in Milwaukee on arthritis on November 10. I have been a patient of Dr. Bernard's for 10 years and now am 62. My condition is rheumatoid arthritis. During this time I have received gold shots, cortizone treatment, received numerous medications for the condition, had surgery for removal of calcium deposits from the knee, and had surgery to cut the tendons in the middle fingers. I have been helped tremendously in my fight against arthritis the past 10 years and am thankful to the doctors who have been dedicated to my case. I have some suggestions and questions I'd like to present to the National Commission on Arthritis to help them in their planning of their resources for the disease and assist them in their long-range goals.

Some of the things I have been wondering about or would like to see implemented are as follows:

- (1) Many people have good insurance policies before retirement; but, after they're on Medicare will their treatment have to be lessened or will provisions be made? Also, what help can people with arthritis receive if they do not have a good insurance policy to cover the high cost at present of treating the disease?
- (2) Will Medicare provide the finances for prescription drugs used for treatment of arthritis or will the Foundation be able to provide some help for the continuous medicines that are needed to provide relief?
- (3) Provide transportation like ambu-cab for severe cases where the patient has trouble getting up bus steps or is unable to drive an automobile.

- (4) Provide physical therapist aides, occupational therapist aides, or arthritic specialist aides to work through the local public health department to make home calls to assist them in therapy and things around the home. If not through public health agencies, then have them work out of the arthritic centers.
- (5) Keep informing the public that arthritis is a dread disease. Arthritis probably doesn't result in as many deaths as some other diseases, but I think people with it sometimes suffer a living death as they live in pain, swelling, and stiffness day after day, month after month, and year after year.
- (6) Keep informing the public that arthritis cannot be cured, but can be controlled.
- (7) Continue the campaign against arthritis quackery.
- (8) Help those who can work to secure jobs according to their personal abilities. Many arthritics cannot work because of the pain and malfunction of their joints in their arms, necks, legs, etc. They also need to rest; thus, cannot hold a full-time job but possibly could do some task if properly assigned. This would help the depression that goes along with arthritis.
- (9) Continue to provide financial resources for the doctors who are striving to conquer the disease so they do not become discouraged and will have the proper research and therapy supplies and equipment.
- (10) Provide scholarships for students in occupational and physical therapy who will work within the field of arthritis. Therapy is one of the most important aspects of treatment and without the therapists, progress cannot be made.
- (11) Update insurance policies to provide for more physical and occupational therapy coverage.
- (12) Keep having hearings and meetings for the arthritic patients to have them express their views and learn from each other. This helps the depression of the patient and doesn't make him feel he is lost in the wilderness.

These are a few of my thoughts on the subject. Thank you for letting me express my views. I wish you and the National Commission on Arthritis best wishes for a very fruitful program.

Thank you again. I will try to attend the hearing in Milwaukee on November 10.



Milwaukee, Wisconsin

November 10, 1975

MRS. MARIE VAN ROSSUM  
Milwaukee, Wisconsin

October 27, 1975

I have suffered from arthritis for more than 22 years. Since the Wisconsin Foundation has been giving talks on various topics, e.g., the proper use of a cane, I have learned in many ways how to cope with the effects and pain.

However, there are a few things that need attention. A big, big thing would be to provide some reasonable transportation for the older arthritics who do not drive. If and when you can get a taxi, it is at a ridiculous cost which persons on social security cannot possibly afford. This would keep them involved in senior citizen activities.

I wonder if the U.S. Congress is willing to make sure as much money is spent on finding the causes and/or cures of arthritis as on some other all but useless causes on which they spend millions. Please give us all the help you can. We want to be useful citizens and enjoy life.

REVEREND W. P. SAUER  
West Bend, Wisconsin

October 27, 1975

I have finished a letter to the National Arthritis Commission: attention Ephraim Engleman, MD, Chairman. I shall send it to the Arthritis Foundation of Wisconsin for the coming hearing on November 10 at the Marc Plaza Hotel in Milwaukee.

Herewith I submit to you my summation of that letter:

- (1) My opinion on the great need for Federal funding of scientists for more intensive research into causes and cures of the many types of arthritis.
- (2) I recount my experiences with rheumatoid arthritis and of the heroic efforts made to reduce the damage and to make it more bearable.
- (3) I boldly offer a suggestion for research in the lymphatic system and its relation to the rheumatoid variety.

Wishing the Commission the greatest success, I am Rev. W. P. Sauer, retired. Please excuse errors. I can no longer write, but I can type.

MRS. ELIZABETH ARMSTRONG

October 1975

Please do something more for arthritis. I have it and mostly in my hands. Some days I can hardly do a thing with them. My doctor has told me to take aspirin. He also gave me a shot of [cortisone] in each thumb, but no more he says. I suffer with this day and night, wakes me at night like a severe toothache, and there is nothing I can do about it. I did buy a pair of spandex gloves, but seems I just wasted my money which I cannot afford to do as I am a widow not working. I sure hope someone does more for me. People who have, it I know many who are 10 times worse than I am, and I sure feel sorry for them. Mine isn't getting any better, in fact worse. I sure hope someone does something soon. Thank you.

P.S. When my husband was alive we attended a couple of meetings and gave what we could, as he had it also.

MRS. CAROL BATES  
Ladysmith, Wisconsin

October 26, 1975

Arthritis is such an accepted disease. Everyone has it, or knows someone who has. So most people assume that a few aches and pains now and then are all that arthritis means. I have had rheumatoid arthritis for the past four years. I am in my fifties, married, and have a 13-year-old daughter at home. My family is very helpful, but I know it must depress them as much as it does me to always have to see if I am able to do ordinary things.

The first year I had rheumatoid arthritis was spent trying to find the medication which would be effective without side effects. This is impossible we have found. I have to travel over one hundred miles to the Marshfield Clinic where there is a rheumatologist. The doctors in our area do not feel qualified to treat this. I am on medication which makes the pain acceptable, and I am able to do much more.

We do need more doctors trained to recognize rheumatoid arthritis. We need more research to find the cause of it, and drug research to find something to combat it without so many bad side effects.

Another burden in having arthritis is financial. I cannot work, nor can I get health insurance because of my condition.

Doctors say: "We don't know what causes it, what it will do, or when it will end!"

It is no wonder the arthritic person tends to become depressed. Don't we need more research, more doctors and clinics and education of the general public to get more support for these efforts.

Thank you for the opportunity to air my views.

MRS. EUGENE BERG  
Ripon, Wisconsin

October 24, 1975

I most certainly think we need more work done for people with arthritis. We should have more research done on what it comes from and help for people with it.

Do you know what pain it is with arthritis? I have had arthritis for about five or six years and I am in so much pain, almost constantly, that sometimes I don't know if I'm coming or going. I take aspirin, but that doesn't help either. I am now wearing a collar because I have a pain in the back of my neck and it runs down to my left arm, leaving it numb most of the time. I also have it in my wrists and arches in my foot. They say I have calcium deposits pressing on a nerve in the back of my neck which makes my arm numb. I am 62 years old and could do a lot of things if it weren't for that.

It's pretty hard when you live alone and have to do everything yourself. I sure hope something will be done to help us. My husband also had arthritis for several years before he passed away. He took gold shots, but still had problems. My father also had arthritis very bad and had all sorts of problems.

We need research, training, development, information, continued education, better care, treatment, and diagnosis. We need medical professionals, community service agencies, and public and private community funding.

MRS. ROSE BETHEL  
Oregon, Wisconsin

I am a sufferer of this disease and don't think the doctors in charge go far enough to explain what can happen to one that suffers. The doctors do not tell you of eye or tissue troubles until you have gone through misery untold. Then when you treat eyes for glaucoma, they never tell you of the side effects of the drugs until you start asking questions, from suffering from drugs elsewhere in your system. More should be told to the public, as all sufferers are not alike. I was happy to get the information on "eyes" after much suffering and misery and expense.

MRS. ARDIS BOYNTON  
Beloit, Wisconsin

October 25, 1975

I have had arthritis in my knees for several years. When it first began, my doctor (who has since retired) gave me shots which stopped it completely for two years. Since then it has gradually grown worse, and nothing seems to be of any help. I have been to two other doctors and the arthritis clinic at Madison, and the verdict is always the same; "There is nothing we can do for it. Just take aspirin and keep active."

I have kept active, and I know that is good advice, because if for any reason I neglect to do that, the lameness is immediately worse. I do



exercises for half an hour every morning, take care of an eight-room house (with toilets in the basement and on the second floor), take care of a lawn (except for mowing), and a garden. Am also active in several organizations and really work in them. It becomes increasingly difficult and painful to walk, and I have to use a cane (or a rake, hoe, or shovel).

I cannot take aspirin or any like medicine, because since having an attack of Manieres Syndrome four years ago, they all have a strange effect on my head. Have tried aspirin, Ascription, Anacin, Tylenol, and Bufferin.

In the Wisconsin Arthritis Bulletin several years ago there was a Statement made by someone that "any doctor who tells you he can't do anything for arthritis is doing you a great disfavor." So far I haven't found anyone who tells me anything different, except to suggest surgery.

As far as anything I have been able to learn, "stubbornness" is the only antidote for arthritis!

MISS BESSIE BROOKINS  
Sheboygan, Wisconsin

October 28, 1975

I can't know what could be done to improve treatment for arthritics.

It does seem doctors should be more concerned. I am 80 years old and a year ago last March I broke my hip, and it has not improved my health and ability to work. All they seem to advise is to exercise and take aspirin. The aspirin has my stomach raw and I am too tired to walk any distance. Doctors say everybody has it.

LUCILLE E. ROBINSON BUSH  
Milwaukee, Wisconsin

I wish I could attend your meeting, but as an arthritic (rheumatoid) I have no way of getting to your meeting place unless my husband takes off from his work (teacher) and takes me. I have not been able to afford taxis, as the cost is prohibitive, and I cannot climb the bus steps. (I have had difficulty in seeing doctors--who make appointments during school hours and not on Saturdays it seems. Organizations have no help for people who live west of 35th, I was told.) I wonder how many other arthritics are unable to attend because they are housebound most of the time? Couldn't some way be found to provide transportation to doctors, or hospitals for hydrotherapy treatments, or just to meetings like this in which we have a stake and vital interest? Many of us are on Social Security (Medicare); I am lucky enough to have a working husband. But some can't afford taxi fare, at that, for repeated trips. I have been hospitalized twice for operations, and a combination of Blue Shield and Medicare does not pick up the tab. How can people existing solely on Social Security get the care they need and pay their bills? As a former teacher I have a small retirement income, but I will hesitate about future operations as the cost is putting medical help out of my reach. I no longer see a doctor--depending on aspirin only to get me through each day.

I try to exercise moderately but have trouble doing much at home. I hope I am doing the right exercises. I know the disease is progressive, and, I find, more and more crippling, in spite of what I am doing. It is more difficult to dress, to do simple household tasks, to climb stairs (I pull myself up on a banister), to comb my hair etc. My husband is most helpful, but he has a job and can't be in two places at once. Getting down in the bathtub is an impossibility, but I do have a shower. Wouldn't it be great to have some of the tools hospitals have (hydraulic tub lifts, etc.) in the homes of patients who need these and can't possibly afford them without help from the Arthritis Foundation? Are you spending money on hospital equipment to help patients or all arthritics--those not in hospitals, too?

Money sent you seems to have gone for research--not to immediately help the arthritics, who are unable to pay for helps they need. How many years are you going to continue "research" exclusively and not get results? I realize the Arthritis Foundation is poorly subsidized--compared with some Federal helps to other disease groups, but other groups try to help individuals too--iron lungs, artificial kidneys, etc. are available. How does your organization really help in all these years? I want a cure found, naturally, for this dread disease, but sitting in my little chair, a housebound victim, I wonder who the researchers are and what they're really doing to help or try to help us? Meantime crippling increases and adds problems we can't afford to solve without help financially. Do you really care? Does Ford? Forgive me if this sounds a trifle bitter. My share (as an arthritic) of what your Foundation has done for me is one little pamphlet given me by a doctor in the hospital stating that "There is no known cure for arthritis." How many of your booth attendants at conventions, state fairs, etc. are arthritics and are concerned with research in this? How many of you gentlemen in charge of this Milw. Branch are arthritic? How many at National Headquarters of "A Foundation" are? If you are really concerned, why isn't there better organization of both raising funds and doing coordinated organized research? I feel, while money for your organization is inadequate, it is being frittered away by unconcerned bureaucratic personnel and inadequate administration and supervision. You lack control, it seems to me. Its a "la-de-da" organization and "bumbles" along really never expecting results.

If I am wrong in my estimate it is because you haven't gotten your "image" across to me (an arthritic) (and I think the public) any better than that. You better communicate a better picture of results. Sure, we're concerned!

(Enclosed a few research suggestions. I know nothing about how you spend Arthritis Foundation funds. You must report to someone. That someone is keeping it a "deep dark secret." You may think these are naive. I think they are fundamental to organization.



Research Suggestions

Get Rid of "Dead Wood" (just in research for financial support) and get a deadline for results.

- (1) Do you have a central science building for research with full-time scientists employed with (renewable yearly contracts or) grants that are accountable for results to a board consisting of 3 arthritics, (concerned) 2 physicians, and another (outside) scientist conversant with physics or chem and able to judge projects of research and recommend grants continuance yearly? A Central Bldg. is essential to control--a research center.
- (2) Do your research scientists have access to the work of doctors throughout U.S. and foreign lands? How do they get this? Have they a chance to experiment with patients themselves?
- (3) Why are arthritics not registered through doctors and hospitals with your Foundation (by name and address) so that research surveys could be sent them? You should get adequate (geographical) and cooperative response from arthritics to get organizable data on "common denominator factors." Questions of psychological and physiological impact could be considered in the surveys. I think you'd get a response, too.
- (4) What research of alleged cures in other countries for verification or immediate study of drugs etc. and their potential or danger is being done?
- (5) How are efforts of doctors in this country coordinated? How do you encourage them to send you their results of practice with arthritics? A magazine like the Medical Journal--with prestige for doctors results published might be one way. I feel you are paying out amts. to part-time researchers (doctors) in arthritis, and doctors should be controlled that are in this work by your organization (if you are paying). Why subsidize hospital Clinics in this, when the doctors are receiving adequate pay already (as are hospitals) from patients? (Rather subsidize patients who can't fees financially alone.) Keep your money for full-time researchers, and if they produce no results in a reasonable (3 yr. period)--get new men in, who think and work along different lines of experimenting. Men who work only on this. Results of all experiments should be filed so not duplicated, ie. (Examples of types of possible research)
  - A. Chemical Blood changes--Is there mineral or vitamin imbalance? (Do we have even Norms yet?) (Why do some patients receive help from mineral hot springs? Is diet a factor? Is a virus involved? If so, how can it be destroyed without destroying the patient?)
  - B. What glandular changes?--Can output of gland secretions be measured? Are balance norms established? How do arthritics differ? (Adrenals affected--why?)



- C. What psychological and physical factors trigger (initiate) disease? Are hereditary factors in? (Surveys)
- D. Are there specific scientific investigators working on alleged drugs or cures from U.S. and Foreign lands to test results immediately? Who releases information?

Coordinate efforts of doctors and scientists--Better communication! A monthly publication sent to arthritics and doctors and pub health outlets on research accomplished (each mo.) could be job of administrative coordinator and serve as a public informational service that would help raise funds and monitor work of scientists hired. Computers for use of scientists at Central Arthritis Science Foundation Bldg.--(eliminate as much clerical staff as possible. Have people who can feed data in, and interpret results rather) Coordinating Administrative Director (full time) to supervise work projects (time control etc.) of scientists hired necessary. Responsible to board for results--and his job. (Divorce money raising for this from research buildings.)

P.S. Not enough is being done to get funds for this--apathy? Why not yet (Roz Russell or people afflicted) to raise funds as is done for muscular dystrophy? This isn't a well-bred polite, pany-waist disease--Lets hit it! Get someone in who can do the job! Get organized.

You have my permission to read this aloud, send it to President Ford or any other official in or out of your organization--or simply to file it in the wastebasket (as I suspect will be done). I am not a crank, but a tired arthritic. Tired of apathy when it comes to stamping out a disease afflicting not only myself, but 6,000,000 or more Americans. This is a sad disease for those who suffer from it. I have a master's degree in education and cannot do the job I love--teach. We are a loss to America and our families. Can our nation afford this loss? Your organization is our only hope for help, and it is letting us down daily. Yes, money is needed, but also a crusade of intensely concerned individuals with ability to organize this Foundation into something that can obtain results.

I pray my "sounding off" will be taken seriously and some changes for the better will result (even a shake-up and energizing spirit in this work) and in finding a cure.

P.S. Please excuse writing--I can't type now and even writing is difficult--but I must communicate. This is important to us.

PHYLIS CALLAN  
Milwaukee, Wisconsin

October 24, 1975

This is in response to your letter of October 17 asking what it is like to be an arthritic person. I'll say first, you have to have it to fully understand. My mother had it for 30 years but I did not know what she went through until I had it.

I cannot complain too much as there are many people in worse shape than I am in. It started in 1967--mostly in the lower back and then gradually every joint in my body was affected, even my jaws hurt when I ate. I went through the whole gamut--Indocin, Butazolidin, aspirin (up to 16 a day). I guess all this medicine finally affected my general health. I lost weight, looked like and felt like I would be an invalid for the rest of my life. I did as my mother had done--she tried everything and finally just stopped going to the doctor and lived with her affliction. After stopping all medication my general health finally improved. Gradually I regained some physical strength and now do my housework and get out. I have osteoarthritis--I am 75 years old now, and have had trouble with my joints for seven years. I get along all right walking on carpets and grass, but have difficulty when walking on concrete. I do not stay on my feet too long at a time and manage well enough. So many people are much worse off and I'm grateful I get along.

For suggestions--It would help if something could be discovered that would prevent aging joints to become painful. When your knees hurt when you walk, you are not active enough to keep the rest of your body in shape, so you begin to deteriorate all over. I'm so grateful that I have recovered to the point where I am, but every year I can do a little less. I hope some day science can discover some magic to relieve the suffering of millions. I have heard it said that arthritis does not kill you--sometimes you wish it did. Take pneumonia--you either get better or die, but with arthritis it just hangs in there.

VIVIAN CLARK  
Milwaukee, Wisconsin

October 26, 1975

I have gout. No one knows what the excruciating pain is like except another person with gout. Many nights even the bed hurts. Nothing seemed to help until it was properly diagnosed, which finally happened after a visit to a second doctor. The first doctor, an orthopedic, never took a uric acid test--just wanted me to take the powerful arthritis medication, which is why I resorted to a second doctor.

The gout medication has now taken hold and gone until I really overindulge in food and drink. I know it has been proven that diet is not necessary with gout. However, you do not realize how much food is high in purine until you look at a list. I do believe watching what you eat and drink is also important to a gout patient. Of course, moderation is important to every person whether you have an illness or not.

My doctor says gout is hereditary, but I cannot come up with anyone in my family with gout. This is one area that could be researched. Is it always hereditary?

Being in the menopause years, I also have a degenerative form of arthritis. There are spurs and widening of the discs. This causes a great deal of pain, especially in the right shoulder. The doctor suggests a neck collar for sleeping if the pain becomes intolerable. So far I have been able to tolerate it. This too is another area for research, menopausal arthritis.

After my experience with an orthopedic physician and his not detecting the gout, I think they should be alerted to test for gout. I went to an orthopedic doctor because of the severe pain in the knee. I should have gone to my internist first and would not have had the pain for so long.

Thank you for reading my letter. I know several people with other kinds of arthritis and know I am much more fortunate than they.

JOHN M. CLOCHESY  
Fond Du Lac, Wisconsin

October 26, 1975

There are unmet needs of persons suffering from arthritis. We need trained professionals dealing with arthritis and related diseases. Health professions need: (1) research, (2) training, and (3) continuing education.

The public needs: (1) information and (2) better (specialized) care and treatment.

Funding is necessary for all five (5) needs listed above--the funding needs to start now!

RUBY NELSON ENNIS  
Sturgeon Bay, Wisconsin

October 28, 1975

I am writing in response to the letters sent out asking for information as to what can be done to help arthritis sufferers.

My husband passed away September 9th, due to complications from rheumatoid arthritis.

When he was 40 years old this started in his feet, and he was told he had flat feet. He bought special shoes with expensive arch supports, and he wore these for a while and got some relief.

To make a long story short, his arthritis seemed to be triggered off to a much greater extent after he had a bout with pneumonia in 1964 and he was given penicillin, which he had such an allergy to that it almost killed him. This was the first time he had penicillin, and he was unaware that he was allergic to it. As a result of this he couldn't work anymore.



We lived in Chicago at the time, so as we had had plans to move to Door County when he retired we came up here to live.

We went to a doctor here for six months, once a week, and he treated him for arthritis, giving him Alka-Butazolidin. This would take the whole afternoon, with all the waiting in the doctor's office. The medication didn't seem to help my husband, and after six months the doctor came into where we were waiting in the little cubicle and announced that he didn't think my husband had arthritis at all but that he had some bizarre disease. He said that he couldn't do anything for him, but we should seek help elsewhere. He didn't even say he was sorry or was the least bit compassionate. To say the least, I was so shocked at the way this so-called professional man acted I couldn't talk.

We went to another doctor and he gave him Indocin...this gave him some relief but it made him sick to his stomach. He was then put in the hospital for therapy, and he felt some better. They had a Hubbard tank which seemed to help. They took x-rays of my husband's feet, and the bones were deteriorated, as were the bones in his hands. Needless to say how he suffered.

I then wrote to the Arthritis Foundation for the name of a doctor who was in this area and who was interested in arthritis victims. They sent me three names of doctors in Green Bay, and I called all three and only one would accept an arthritis patient.

He then put my husband in the hospital again and started him on gold shots. This helped him for a while, but after taking them for two years he started going downhill and went from 175 pounds to 115. He would take booster shots every month after getting a certain amount of milligrams.

I was so worried about my husband, I would talk to the doctor and cry, and said he couldn't eat and was slowly fading away. He said he wasn't worried about his appetite and that was that. . .he couldn't do anymore for him. My husband was in such pain as only an arthritis sufferer knows, and I was worried to death.

I heard about a doctor in Mexico who had treated arthritics successfully, and I talked it over with our Pastor. He said we wouldn't have anything to lose if we went there. I borrowed the money from the bank, and we flew to California November 10, 1973. We crossed the border to Mexicali, Mexico and saw this marvelous Mexican doctor. He gave my husband a thorough examination and started him on Vitamin B shots. . .6 in the morning and 6 in the afternoon. We crossed the border twice a day. He also gave him a white capsule which he called procaine. After three days my husband started to eat and was on "Cloud Nine," he felt so good. While at the doctor's office we met people from all over U.S. who came there for different ailments. This doctor doesn't make any claims to cure arthritis, as we know there isn't any cure. He is a general practitioner and treats many ailments.

If you want to know more about this doctor read the book And the Stars Sang Together by Naomi Tangen Kolstad. She is from Alexandria, Minnesota.

She had rheumatoid arthritis so badly she was incapacitated, and she lied in bed at Mayo for weeks and couldn't get help.

As you know, Procaine isn't allowed in the U.S., due to the A.M.A. and the F.D.A. The doctor in Mexico said if my husband would have come six months later it would have been too late for him. Anyway, after being there a week we came back home and my husband picked up, so he went up to 150 pounds and had to watch his weight so he wouldn't gain too much. He went out with me just about every day and continued to take his medicine.

Then last April he got a gallbladder attack and was taken to the hospital here in Sturgeon Bay and was taken off this procaine and given Motrin, which made him very ill. The doctor also gave him nine Ascriptin along with this. He was in the hospital for two weeks and came home; and after he was home he started going downhill. I took him to a Green Bay hospital and the doctor put him on Prednisone. . . this helped him some, but after he came home he got blood in his urine and broke out in a horrible rash. I had to take him back to the hospital and he contacted pneumonia, and he passed away September 9th. Is Prednisone supposed to be a cure-all for every ailment. I understand they give it to cancer patients, too.

My husband was one of the arthritics who did not benefit from hot weather. He felt better in the colder weather. Spring was a very bad time for him. I could go on and on about arthritis. I don't mean to be disrespectful toward doctors, but we have had some very bad experiences with them, especially in this area. They are little doctors with big egos.

On his death certificate they put the following as the cause of death: "Acute renal failure due to bronchopneumonia." (And this was due to generalized crippling rheumatoid arthritis.)

While in the hospital I had an experience with a doctor that has been on my mind, and I would like to report him to the A.M.A. Our regular doctor would come in twice a day, but this one day he didn't come in to see my husband in the morning, but another doctor came in. He asked me to tell him about our experience in Mexico, and I related it to him. He had his nurse with him and he told her to listen and she would get an education.

After I told him about the Procaine he said he had been giving that for years. I was so taken back, I told him that wasn't allowed in the U.S., and he asked me why. I told him because the A.M.A. and F.D.A. wouldn't permit it. He said they must have changed the law then and just about called me a liar.

Then I said to him, "When my husband gets better I will have to bring him to you for Procaine." His reply was this. . . he looked at my husband and sneered and said, "I wouldn't treat a lame horse." Tears came to my eyes, and I couldn't speak to think that he called himself a doctor and would say such a thing. His nurse had walked out of the room so I don't have any witnesses to what he said. But I think he is an evil man and should have his license taken away. When he left the room he said, "I

hope there isn't any ill feelings." I couldn't answer him but I sure would like to report him to the proper authorities. There have been other incidents about this same doctor that have been derogatory.

It seems a shame that they won't allow the same treatment here as in Mexico.

Now for what I think should be done for arthritis sufferers: More qualified doctors, more research, more therapy facilities, and especially DOCTORS WHO ARE HUMAN BEINGS. Doctors shouldn't be allowed to treat arthritis if they don't know anything about it. Dr. Engleman, I don't know whether you have taken the time to read this letter, but I have only scratched the surface as to what my husband went through. He suffered so and was so incapacitated at the time before we went to Mexico, he was almost bent in two.

We have had some very bad experiences with doctors, and I think they should have to have their licenses renewed after going to school and renew their education along with a course in compassion.

I pray every night they will find a cure for arthritis, and I don't feel that there is enough being done to find a cure, or at least some help.

In losing my husband I have suffered a great loss and am very bitter towards some doctors. The inconsiderate ones make it bad for the good ones.

MRS. EURICH  
Sheboygan, Wisconsin

If you have never experienced a sleepless night, due to excruciating pain due to arthritis, muscular rheumatism, or whatever other name can be tagged onto it, you have Never endured heart-rendering pain. Only the devil himself could have thought of a thing like it (arthritis or call it by whatever other name you will).

They can find money for sending men to the moon (all for what?). God said in His word, "The earth belongs to man, the Heavens belong to ME (God)."

Yet they can't find money to do research to cure or even alleviate this dreadful condition.

Pills help for only a very short time--then one is right back where one was. Some pills have very bad after effects--I know.

If one with muscular rheumatism has tried most every pill and most every balm and salve obtainable, with or without prescription--and I know what I go through 7 nights a week, 52 weeks of the year!!



In the daytime, as long as I keep moving, I have less pain--in spite of stiffness--but nights I cry to God for mercy.

So much money goes up in smoke from smoking materials and a lot more money goes down the drain from drinking materials.

If only some of it were diverted to the cause of helping arthritis and rheumatism victims. Surely God in Heaven would see and bless their efforts--perhaps even guide minds to a simple solution.

Knowledge comes from men!--But Wisdom comes from God!

It is said, "God helps them that help themselves". All very true, but He does not expect us to leave Him do all the pulling, while dragging along in the rear.

So let those who have the "means" and still others the "know-how" get on with the job at hand and pay heed to the tremendous cry for HELP.

I for one cry loud and clear and pitiful daily and nightly. P.S. There must be 10,000 people in Sheboygan County with some sort of arthritis, etc., etc. No date.

ELOISE G. FOLEY  
Sun Prairie, Wisconsin

October 29, 1975

I have had arthritis for very many years. I have rheumatoid arthritis. I live in a climate that partially contributes to my arthritis, becoming more painful at wet, cold seasons. The heat applied and medication in moderate amounts help me temporarily.

Once it's in the blood stream, no cure, and I try to be resigned to that fact. I have had an implant, a plastic kneecap. My surgeon was Dr. H. Mahaffy and Dr. Robert Bonefrake, Jackson Clinic. The surgery was performed at Methodist Hospital. My internist is a great doctor, and Dr. Mahaffy is tremendous; and had my final checkup in May 1975.

My fingers are swollen and arrested case. It's going into my right ankle, now. I still take as little medication as possible, because it affects my kidneys. We have made a great deal of progress, thanks to good doctors and research in that area.

It's hereditary, as my daughter has it and five children. I have 14 grandchildren--expensive but great.

P.S. I've seen many afflicted with arthritis at Colonial Club here. Some live with the pain and others try to avail themselves of the surgery and medication available to everyone. We have talks at various times by nurses who are qualified to discuss arthritis. One wastes one's time talking to some older people and young ones too, to try to help them. I visit nursing homes and talk and distribute shampoo (Breck), which my son sells. They are not samples--expensive but good.

MRS. ETHEL FORSYTH  
Waukesha, Wisconsin

October 23, 1973

I have had arthritis since 1956. In 1968 I was admitted to Memorial Hospital, where I spent four weeks. I am some crippled in my hands. My back has been the worst. I have worn a brace on the back for over seven years. At times the back is very painful. I think more studying should be done before it gets too bad. My doctor sent me to a bone specialist. He called it Osteoporosia. Also, in 1950 and 1951 I had bursitis in both shoulders.

I live alone and try to do my own work. I don't like to give up because I think that is the end.

MRS. LIL GAROT  
Green Bay, Wisconsin

October 27, 1975

I am pleased to relate my experience with my arthritic knees. My legs were bowing out and every step was pure torture. I was advised to have the Marmor knee put into each knee. (Or end my days in a wheelchair.)

In 1974 I had my first surgery. I was in the hospital 29 days, with therapy after the 4th day. My leg was in a sling all day (quite painful) and it swelled terribly. I left the hospital with a 94 degree bend in my new left knee and continued my therapy at home. I now have a 104 degree bend in this knee.

In 1975 (March) I had my second Marmor in the right knee and really noticed a big difference in the therapy from just a year previous. In this one year they made great strides and I believe much progress. They no longer used the sling and my knee did not show any swelling as such. We did not use crutches as in 1974, but canes. I was able to leave the hospital with a 120 degree bend, which I still maintain. I did have to go to the therapy class three times after (to be sure all was getting along fine).

The exercises are cut to two full ones a day with three on the bike. In 1974 it was three full exercises with four bikes per day--but for a longer period of time. This gives me more mobility, I believe. Only when I am very tired do I have discomfort or pain. I strongly recommend this type of surgery for arthritic knees. I walk better; my left leg is quite straight and I know my right one will be, too. I have unbelievable pep.

I sincerely hope my testimony helps someone through this type of trouble.

ARLENE HANNI  
Cuba City, Wisconsin

October 23, 1975

I am writing in regard to what I feel about what should be done for arthritics and what it is like to have arthritis.

I don't exactly know what to say about having arthritis, mostly that I don't want it. It is hard for someone without it to understand the constant pain and restrictions caused by it. My father had arthritis and I did not know, had no idea what he was suffering until I myself got it.

I've had rheumatoid arthritis for 16 years and have many joints destroyed. I have total knee and elbow replacements which have kept me able to take care of myself and do most of my housework.

I think the most urgent thing to do is to research for a cure.

CLARION W. HAUGEN  
Beloit, Wisconsin

October 23, 1975

Dictated to my wife, Mabel Haugen.

My first attack of arthritis was diagnosed as a recurrence of rheumatic fever I had experienced in my teens. The doctor administered shots of cortisone. A year and a half later, the second round was more severe and the cortisone brought on cataracts. Gold shots were given, and pain pills were needed every four hours. At a Rockford clinic I was given Indocin, the first patient to receive it there, and within a week I was able to walk with a cane.

Now, several years, and thousands of Indocin and pain pills later, I am confined to my chair, but can again walk with the walker with help getting onto it, from the living room to the bedroom. I cannot tolerate sitting in a wheelchair, but have a padded, electrically operated chair-seat lift to get me on and off my feet. This spring in Madison, the doctors from an orthopaedic clinic planned to install plastic joints, but my general health would not permit. All of this is just a skeleton plot of what arthritis has done to me.

However, even my wife, family, and pastor claim that I am in better spirits than many healthy people, and although I never give up hope that someday there will come a breakthrough, I don't let it ruin our lives. There are things that we have learned in home care that we had to learn the hard way, and it is too bad that each town cannot have training programs. Through love and cooperation we learned to deal with each problem. The worst of these was running sores on the buttocks which neither hospital was able to heal completely. A pharmacist friend suggested we try Karaya Gum Washers, such as used around a stoma. They worked, and now it isn't quite as painful to sit in my chair.

Circulation, of course, has been a bad problem because I can't really get much exercise. We have a portable whirlpool foot tub, but would like to be able to obtain a knee-high type, so that the legs would get more



circulation. These do not seem to be available--and even if they were--we could not afford them.

I know if anything is done for the millions of arthritics, it is probably too late to benefit me, but might I suggest that instead of spending quite so much on laboratory research, that actual patients be used? We try anything anyway (that's why so many of them are taken in by quacks). Also, it would be a boon if trained therapists could come to the home and teach the person in charge of home care how to exercise the patient and perform therapy. Perhaps some patients could even afford such training, but not us.

People may look at the arthritic rather strangely when he predicts a change in the weather, but it's a painful prediction. Others may think it strange that I require so much bed rest, but my doctor doesn't think it odd. I haven't yet lost my sense of humor or my faith in God. I pray that the Commission will be able to help others before they get to this stage of arthritis.

#### MABEL HAUGEN

Re: Clarion W. Haugen; born May 18, 1909. At the time he was stricken with arthritis, he owned and operated a hardware store in Orfordville, Wisconsin, and twice received the Hardware Retailer of the Year Award for Wisconsin, and once the National Award.

He was a Master sheetmetal worker, and installed heating plants in homes, schools, and churches.

This was over 10 years ago, and we had to sell the stock and go out of business. Mrs. Haugen worked at a small liberal arts college, but had to give up her work to stay home with him this year. He is an inspiration to others, but it doesn't seem right that he should have to suffer; but it is like him to hope that help will come for others.

DON HELM  
Oshkosh, Wisconsin

October 26, 1975

Being 59 years old, I well remember the annual outbreak of the polio season, the grief of families I knew having one or more members afflicted by this dreadful disease, and then the widespread rejoicing when the Salk vaccine gave the dark cloud a silver lining.

Since September 1953, I have worked for the Ted Hoyer Co. making invalid lifters and other aids for the handicapped, and I am happy to be able to help people less fortunate than myself. The Hoyer Co. hires more handicapped workers than 100 percent able-bodied, and while I never dreamed of joining the ranks of the handicapped, my hands are now the least capable of any of the 17 employees in the shop. I am still able to work 4 1/2 hours per day at lighter jobs, get in my doctor-demanded mid-day rest period, and still carry on home hobbies --gardening, etc.

About 1960 I couldn't understand how Ted Nitke, a fellow worker with a clamp for a left hand, could have so much pain at the slightest bump of arthritis inflicting joints on his right hand. I found out a few years later when it hit me, sometime after I became a grandfather. I'm not complaining, some guys don't even get to be grandfathers. Since then I've gone through the swollen knuckle state, been hospitalized for treatment and education, been on numerous drugs (now only Ascriptin), use sauna cabinet daily before range of motion exercises, have had corrective surgery five times since 1970--synovectomies, plastic knuckles, etc. I often say, "I just have to do things differently!"

How wonderful if I could live to see arthritis eliminated, or at least much more alleviated; not that I could be helped at this stage, but many millions of people could have a more enjoyable life.

Enclosure: Ted Hoyer, founder of Ted Hoyer & Company, Inc., had a deep understanding of the problems that confront the severely physically handicapped. At the age of 16 he was injured in an automobile accident which left him completely paralyzed from the chest down. Following months of frustration that he could no longer walk, the realization came that he must do something to help himself live a useful life. With the help of Victor Hildemann, present plant research engineer, Ted designed and developed numerous devices to help him live a rich and full life. The desire to be even more independent was realized when Ted married Marie, a registered nurse, in 1953. Two years ago Ted wrote: "My own personal rehabilitation is far from complete. I must work hard to build soundly my theories on rehabilitation so that when I'm not around anymore, the job will be carried on." Unfortunately Ted passed away in 1954, but his thoughts on rehabilitation and his inventions, which are helping so many people, are a living memorial to him. His disability was truly opportunity in disguise.

MRS. FRANK HOUSE

October 26, 1975

Sorry I cannot help you very much as I would like to. I have osteo and now my hands are getting numb. The doctor here has put me on Motrin 400 mg. I have taken them three weeks now, and find not much difference. I am 79 years old, so I think there is not much I can do. What we need in this town is a doctor on arthritis. I have taken aspirin for years and they do not help any more.

MRS. E. A. HUETEL  
Wabeno, Wisconsin

November 2, 1975

The Minnesota chapter sent me the literature that I asked for by return mail.

When your letter came it was impossible to get an answer back to you by October 31. I am so crippled from arthritis I find it hard to walk the far ways to my mailbox, so my mail is brought to me by some of the young folks, and it is late in the day.

I have taken medication steady for arthritis for several years. It is Ecotrin. Then a different doctor prescribes a two-color capsule. Well, I have both on hand to hold the severe pain down. I get my most help from chiropractic treatments; they find the very sore spots in my body. If only I can get there often enough to have treatments, that is at Antigo, 33 miles from here. I cannot drive, and my husband is deceased, so must depend on others to take me. Lately it was three weeks in succession, before that it was four weeks apart, and at times two months. The hand I am writing with has arthritis in all fingers except the small one. The upper part of my left leg has a twisted cord from a fall March 20, 1974, and then I caught my left foot behind a parked stepladder and broke my hip on May 30, 1974.

I sent for the literature on arthritis to study it and find things that I could do to help ease my arthritis pain. It is in all parts of my body.

I was 77 years of age on September 14.

I certainly would be happy if some sort of cure could be found for arthritis.

JOAN KOTHBAUER  
Eau Claire, Wisconsin

October 22, 1975

This organization is not a non-profit organization! My answer to your questions are there is no need for research, as its been going on for 10 years and little help has been offered the poor people who need it. The rich and in people get it. The rest are taken for all they got and then told there is no more that can be done. There has been case after case of a wrong diagnosis--I had to have surgery on my elbow at 17--I had no rights to refuse that surgery! My husband and I now know I was took for my money when I was single, poor, and trying to survive on my own with no help offered from no one without a price! We know case after case where surgery wasn't needed--a change in climate helped! Certain shots helped others, but only because the doctor wasn't after all he could get and administered the drug in proper amounts. We know people who sued the quack doctor and got rich in return, if his aim (to get rich, buy a home, 3 cars, a plane, a boat, etc.) was a good case. In Wisconsin the medical field has gone to pot! Doctors no longer take an interest in a patient or listen to what he says. They don't care if the patient is helped or dies --is even more crippled by a mistake!

The Congress passed a very bad bill if it is going to give more money for quack doctors who claim they are legitimate and can help arthritics. Three-quarters of the time the doctor has been wrong in the manner he treats his patients--like cows on an assembly line. We the people of the U.S. need jobs that pay good money so we can support our families--what is happening is people are being laid off their jobs and no longer able to support themselves because there are no jobs to be gotten! God Bless Watergate (our country)!



Milwaukee, Wisconsin

November 10, 1975

FERN MARCKS  
Pepin, Wisconsin

October 23, 1975

As one who has had arthritis for nearly 50 years, I appreciate the work being done by the agencies who deliver services and information to arthritics.

I have benefited by total hip surgery, and I appreciate the research which has made procedures like this possible. Information supplied by the Arthritis Foundation is also very helpful.

MRS. DONALD MATTHIAS  
Berlin, Wisconsin

October 22, 1975

I am a 40-year-old housewife, who has had rheumatoid arthritis for five years. I got the disease over night, and within six months it took over my whole body. There is no stopping it! You go to a doctor and get something for pain, and all the time this terrible disease is destroying your body. It's really a scary thing--knowing nothing can stop it, and some day you won't be able to move.

The pain at times is so great--night and day--that I've prayed often to die.

I hope some day soon there will be enough funds to help find a cure.

MRS. ALMA ROSE MILLER  
Reedsburg, Wisconsin

October 25, 1975

I am a housewife, age 66 years of age, and have had rheumatoid arthritis since 1955 and know of the pain and suffering that goes with it. And also have other diseases caused from it, so am not able to do the things which should be done. Have had total hip surgery on both my hips. The right one almost two years ago and the left this past August. So still not completely over it. The most urgent need that I know of right now is the arthritic clinic being closed, and why is it? I was told this yesterday when I was there for an appointment. I was shocked as I know it will affect many people with arthritis. And also will be losing a very good arthritic specialist who will be leaving.

I am very concerned as have been doctoring there with good results. Some of the unmet needs I suggest are: research, hoping for a cure, training, continuing education, better care, treatment, and diagnosis. How to meet the needs could be through the Federal Government, donations, collections, etc. I would think that those who should articulate before the Commission would be the medical professionals, allied health professionals, elected officials, community service agencies, community funding sources, (public and private), people with arthritis (if able to attend). I would very much like to attend the hearing, but my health does not permit it.

Milwaukee, Wisconsin

November 10, 1975

IVA MORRELL  
West Allis, Wisconsin

November 1, 1975

I'm a widow. My age is 71. I've had rheumatoid arthritis for 27 years, and perhaps longer.

First, two sons arrived. When the second son became 18, our last child, a daughter, was born. When Linda reached the age of six, she attended her first day of school. At noon when she came for lunch I can remember my left hip breaking and me falling to the floor. My broken hip was the beginning of many surgeries.

In 1966, my husband passed away, due to lung cancer. For the next two years I faced a real struggle. My pastor came to my rescue. He convinced me I should move into the M.M. Health Center.

Mr. Fullerton was in charge of the Health Center, and my pastor, Rev. Spear, contacted him, and soon the plans were completed. As of last February I've lived here five years.

Now this paragraph will be an unpleasant one: (1) surgery on left hip, (2) surgery on right hip, (3) surgery on right arm, (4) surgery on left arm, and (5) second surgery on left arm. I sincerely hope I shall never undergo another surgery.

P.S. Dr. Milton C. Borman cared for me many years. I couldn't possibly have found finer care wherever I might have looked. He was highly recommended to me.

C. E. NEUMAN  
Milwaukee, Wisconsin

October 1975

I would like to present this statement in connection with your November 10th hearing at the Marc Plaza Hotel, Milwaukee, Wis.

Let us outlaw the remark: "There is no cure for arthritis," and substitute for it: "Let us find a cure for arthritis."

To do that there must be an open-minded approach allowing all disciplines to contribute to this finding with full publicity given on ideas submitted to arthritics. The arthritics would be expected to give consideration and comments on such proposals and cooperate in implementing them.

Currently it appears that only the medical schools' ideas are publicized by the Arthritic Foundation. Arthritics must be willing to give testimonies as to their experiences. I have solicited appraisal comments from arthritics who have read and/ or applied Giraud W. Campbell's book, A Doctor's Proven New Home Cure for Arthritis; by radio, paid newspaper ads, and talk shows. There were few responses received.

Another similar book is "There Is a Cure for Arthritis" by Padvo O. Airola, M.D.

Some days ago a news story in the Milwaukee Journal stated that a professor at the Akron University, Akron, Ohio, had found that copper bracelets worn by arthritics developed ethylene when contacting the skin. The ethylene reaction gives some relief to wearers. This man asked for a report of the experiences of bracelet wearers. I tried to pick up statements to be forwarded to him but received only two. However, I have seen at least a dozen people wearing the copper rings.

Are not arthritics desirous of being helpful to their fellow sufferers?

CAROL NIEMANN  
Winneconne, Wisconsin

November 4, 1975

- (1) Surely some better course of treatment than the aspirin -- ulcer steroid side effects -- orthopedic surgery route could be devised almost immediately.
- (2) The uninsurability of the chronic arthritic not only tends to drive the person from the job market but to cause the patient to delay or neglect treatment because of the high cost.

MRS. RICHARD D. NILES  
Madison, Wisconsin

October 22, 1975

I am pleased to learn that the National Arthritis Commission is anxious for suggestions for ways to meet the needs of people with arthritis.

My personal feeling is that sufficient funds should be available for (1) basic research -- to understand and attempt to prevent the occurrence of arthritis, with funds channelled through professionally recognized sources, (2) expansion of numbers of centers for the clinical application of research, (3) development of outreach teams (physicians, nurses, and allied health personnel) to circuit ride a State or region to conduct clinics, provide continuing education to professionals, and stimulate educational programs locally, (4) aggressive programs in continuing education for professionals, possibly working with professional organizations and established continuing education programs, (5) preparation of clinical nurse specialists in rheumatology, (6) more attention to patient teaching programs at all rheumatology centers. This could be a major junction of the clinical nurse specialist. Thank you for the opportunity to present these concerns.



SHIRLEY N. NUHN  
Milwaukee, Wisconsin

October 27, 1975

As a staff member of the Wisconsin Arthritis Foundation, I look forward to attending the Hearing.

Dealing with the public is not easy. And when so much of that public has arthritis, it's uneasier still.

The WAF faces a dual problem; other people have noted it, too. First, people should know that arthritis can be very serious and, if not properly treated, will cause physical and emotional anguish for life. They must learn more about it. Yet, not everyone who has an occasional ache or twinge has a serious case of arthritis. This group must learn not to waste their time and that of health professionals.

I don't have arthritis and cannot possibly put myself in a sufferer's place. But if I ever do have it, I'll remember everything we've heard from its victims.

I believe every physician qualified to treat arthritis should take a brief course on human relations, if they have not already done this. The feedback from arthritis victims proves to me that good physical care is far from enough.

I also wish that legitimate firms which manufacture potentially valuable useful products and equipment would take a long look and possibly second look at what their advertising message truly conveys. Human nature being what it is, there always will be people who seek a single pull, heating rub or whirlpool that promises so much and ultimately disappoints them.

About research--there better be some! Judging from the Statements that have poured in thus far, that's what the people want. And it's a question I've been hearing for a year and a half.

About more money--our current economy seems to have produced a decrease in financial assistance for physical ills. Many more appeals are being denied--either that or people are just becoming more vocal about getting it.

"Man on the moon, nothing for earth," is something you'll find again and again. I agree totally. Bring the money to where it counts. Physical misery just does not make for a good America.

I hope you will be greeted by a 500-strong audience in Milwaukee November 20.

Milwaukee, Wisconsin

November 10, 1975

MRS. CORA V. PELT  
Wauwatosa, Wisconsin

October 23, 1975

Unmet needs: Research and Continuing Education.

Articulate the above before the Commission: medical professionals, people with arthritis, community service agencies (public and private), community funding sources (public and private).

To provide more ramps on street corners and into stores for those like myself; can't walk a step unless I have a railing. Ramps instead of steps into doctors' etc. offices where one has to go for services. I do carry a cane. I am one of the aged citizens.

MRS. EDWARD PIOTROWSKI  
Greenfield, Wisconsin

October 31, 1975

When I found out I had rheumatoid arthritis I was 28 years old and had two young sons. I couldn't believe it because like others I thought arthritis was for older persons. I didn't have any knowledge that there are various kinds of arthritis.

The first year I was treated by an internist with Indocin. After not seeing results (because I was told we caught it early) I switched to a specialist starting with gold shots. I shortly stopped gold treatment because of pregnancy and resumed them after the baby was born. The gold treatment worked for a year and a half, in which time I had surgery on my right hand on six knuckles. I didn't want surgery as I was trying to cope with the disease and a new baby, but others (doctors, relatives) felt I should. Even today I feel the surgery was not necessary.

I stopped gold treatment because I was pregnant again, but returned right after the baby was born. This time the gold did not give satisfactory results. The doctor then suggested Cuprimine which I am now taking for over two years with great results. A year and a half ago I was in the hospital for two weeks' rest and found the program they have (talking about daily home problems, therapy, etc.) was very helpful.

One of the things that helped me a lot is my understanding family (husband, children, parents, and in-laws). My husband is very helpful and also the children, now that they are older.

I feel having a good doctor, a specialist if possible, and following his advice as best you can, reading and learning all you can, and keeping away from quackery medicines and items will help you to a better life. We also need more public knowledge of the disease, radio, TV, and self-help clinics, etc. A lot of the things I learned came after it already happened to me.

Eight years ago, when I found out I had arthritis, an older neighbor told me people do not die from arthritis, so you'll just have to live with it. Some days are not easy living, especially when the pain is so bad

Milwaukee, Wisconsin

November 10, 1975

that you think your mind will go. But it is good to know that new studies are being made every day.

MRS. CLARE RAYMER  
Rice Lake, Wisconsin

October 23, 1975

I would like to describe what it is like to have arthritis that cripples you, and you can't even do your housework or any other work, after having been a very active person. To just sit and watch someone else do your work is not encouraging.

I think there should be continuing research and information to the general public. My most unmet need was to have had better diagnosis in the early stages of my arthritis.

I think doctors should have better knowledge of arthritis in the early stages and treatment at that time.

I think that someone with arthritis, especially with the crippling kind like I have, to appear before the National Arthritis Commission and to the Congressmen to show them what can happen to people with arthritis, even in early life after being very active.

There should be some kind of community service agency to finance expenses of people with limited finances, as it becomes very expensive and there is no insurance one can afford to carry that will pay the expenses; and medicare will not pay all expenses either. I think medicare should pay more of the expenses for treatment of arthritis.

MRS. FLORENCE ROGAHN

October 23, 1973

Since June 1973 I have been under medical care for my arthritis. It began with a numbness in my left hand, which puzzled me, so I went to my family doctor. He put me in the hospital for various tests such as electromyograph, neck traction, and heating hydraculator. The mylogram revealed I had a spur between my sixth and seventh vertebrae, and a little in the fourth and fifth. So my case was revealed to be osteoarthritis. I did have two falls on ice in the winter of 1972 and another fall in a powder room at a friend's home on the concrete floor. So I presume I attribute my condition to that. After leaving the hospital with my traction kit I presumed I would get better, but I got so depressed from taking the traction and heating pads three times a day, it became so routine and so time consuming I never left the house. I became nervous, always wondering if I would become an invalid or I would have to face surgery which the doctors said would not be necessary unless I cried "Uncle" whatever that meant. I just became seriously depressed and was referred to a psychiatrist. I got so I didn't know what to do. I guess I just became tense from not knowing what I could do and what I could not do. At this point I think people could get more information on their type of arthritis and what a person can do and absolutely cannot do. Being so confused I just panicked and I am still under the care of a psychiatrist. I take Valium and Elavil. During my hospital stay in the psychiatric ward



I did not use neck traction or heating pads to my neck and seemed to get along well after being up for a while. I do have pain and stiffness in the AM, but it varies from day to day. I do not know my limitations. I wonder if I can go golfing with my husband. None of the doctors seem to give me a definite no or yes. A physical medical doctor at the hospital said I can golf and then another said no. So I am completely baffled as to what to do. Whirlpool baths were suggested so I joined a health spa and I developed a skin rash and went to a dermatologist and said it was very dry skin from the whirlpool. So I discontinued that. Now I suppose you can see why I am so confused. I think many people with arthritis do not know what they can do and what they cannot. Exercise was suggested for me but the doctors don't tell you what kind and how much, etc. At present I am only taking medication from the psychiatrist, Elavil and Valium. I am in constant pain--my whole back being also in pain. I am trying to relax and learn to live with it. I think some things that should be helpful to arthritics is more specific therapy. A program titled separately--one for arthritis of the neck and back and one for other areas. Something like a list of do's and don't's. That would be a great help. I think a lot of people are confused by listening to so many different answers which probably do not relate to their specific case. Maybe some people are too active and shouldn't be and many who are too sedentary and are not supposed to be. I also do not take aspirin because the doctor in physical medicine said I didn't need any medication. I hope you can see my dilemma in my case and hope my letter is helpful, too.

MRS. JOHN F. SAGE  
Janesville, Wisconsin

October 28, 1975

#### WHAT IT IS LIKE TO HAVE ARTHRITIS

This is the most difficult disease to explain--what the feeling is to an Arthritic who has it. To be in constant pain along with the thoughts of discouragement and complete helplessness, and in some cases hopeless confinement with no social activity at all, is very hard to bear. You never know what part of the body the pain or soreness will hit next. At times an arthritic cannot even pick up a common pin, much less carry or lift any weighted object, because of the loss of strength in the hands, arms, and shoulders. There is no feeling in the fingers at all, thereby dropping things, being unable to pull up zippers or button a button.

In my own case, it started in my finger joints at the age 35 after the birth of my son who is now 23 years of age. It has now gone to the joints in my toes and also settled in my back, hips, and shoulders. I can see as I grow older it is slowly creeping over my entire body. I am still active, but am stiff and sore and even more so in the cool, damp and wet weather time, which is a time when the arthritic suffers most severe pain.

I have a brother who is almost completely immobilized with this rheumatoid and also the osteoarthritis. He was just recently hospitalized and was unable to have the operation on his one foot to correct the deformity, which would have let him still walk a bit. He has suffered with this disease and been unable to work for the past 16 years. He was struck down with it at the age of 55. He hasn't worked a day since.

If a person only had the time to apply hot packs, take baths, etc., but it takes an arthritic longer to complete the necessary jobs in a home than a normal person without the crippling disease.

As for our first most urgent unmet need as an arthritic, I would say we should have some physicians who specialize in this particular disease and not to pass it off as "Well, you have a little arthritis there," and get some words of encouragement for relief or help, so we can live a more normal life. There could be outpatient and also inpatient clinics set up to aid these people.

W. P. SAUER  
West Bend, Wisconsin

October 28, 1975

The efforts of your Commission hold promise of leading to better answers on cause and cure in the various arthritis fields. It seems to me that unfunded and poorly funded researchers have done quite well. But a large legion of scientists must be engaged. Who is to provide the funds? The arthritics themselves? Devoted physicians cannot be expected to give enough time to the problems.

Now to explain my own problems. Twice in my later teens I had so-called inflammatory rheumatism in every joint. After second attack tonsils were removed at age 18. Then for 46 years I was fully able to take part in most activities. At age 64 these pains recurred. Went to Mayo Clinic. Diagnosis: Rheumatoid-systemic...prescribed exercises and 18 Ascriptin a day. Back to work for 1 1/2 years. Could not keep on. I might have had gainful employment afterward, but was not able.

Tried Tucson for nine months. Two operations related to rheumatoid arthritis before Tucson, two others while there. Home again; in 1968-70 I submitted to seven operations in Milwaukee. The first, synovial removal from left knee. Pseudomonas got in there (during or immediately after). Then followed two drainage tube operations, one peroneal nerve moved over, then two knee stiffening operations...all these to conquer pseudomonas. No luck. Almost the entire left knee joint dribbled out through that hole which wouldn't close.

Then after seven years I returned to Mayo. After 10 days in isolation my left leg was removed above the knee. Good recovery. After 68 days home with artificial leg. Returned after five months for left wrist and knuckle surgery. Surgeon promised 30 percent usefulness! Achieved. Three weeks ago a further examination advised reconstruction of right wrist to keep the arm from becoming useless.

SUMMATION: 407 days in hospitals and 15 operations; 13 of them under general anesthesia. The 18 a day Ascriptin dosage was discontinued because of extensive rupturing of capillaries; 6 Motrin a day does well as replacement.

Present condition: Using elbow crutches, I can walk well...about 800 feet a day. Can still feed myself, though hands are severely crippled.



Cannot write. My wife bathes, dresses, combs me, helps me stand up from highrise chair positions, and walks behind me to ease possible falls. Friends help her with the latter. She too has had a strenuous life these last 10 years especially.

Comment on help received: I cannot say enough for the medical men, the nurses, the therapists, and friends who have tried so much to make me comfortable. I am deeply grateful for Medicare A & B. We would be more than paupers by now.

I do not expect that much can be learned from the description of my personal experience. But I believe that a theory of mine as to the cause of rheumatoid arthritis in particular could have some value. The field of medicine has always been of great interest to me. Ten years ago I asked the head of the team of rheumatologists at Mayo Clinic, who counseled me how to live with my disability, this question: "Could this disease stem from some breakdown in the lymphatic system?" His answer: "There is no connection."

This did not satisfy. After that I've read everything about the lymphatic system which I could find without asking another MD. First off, I found that tonsils are a part of that system; so since I had had my broken down tonsils removed and thereafter for FORTY-FOUR years had had no recurrence of my painful experience of age 17 and 18. My question at age 65, when those unforgettable pains returned, seems reasonable; namely, where else had my lymph system broken down this time? I learned from reading that tonsil removal does not remove all tonsil tissue from the throat.

I learned further about the marvelous "one way" movement of the lymphatic systems, BEGINNING AT THE EXTREMITIES. Also that these tubes, very thin at first and growing larger, served to pick up fluid that leaked through the venous walls (with its impurities) and returned its load through a pencil sized tube somewhere near the collar bone to the venous flow to enter the heart for purification. Does it follow, my question, that wherever there is a breakdown of the tubes, irritating debris can build, cause inflammation, swelling, and finally, ugly deformations so common in us "rheumatoids?" Isn't it true that the more usual area for these things to show up are the hands, toes, ankles, knees, and shoulders?

What causes the breakdowns? Sure a host of reasons such as hands too often chilled; housewives who must scrub vegetables in cold water, cold clothes rinses, cold weather clothes hanging, etc. Housemaids knees, knees injured in twisting, bumping. Shoulders bruised in various ways. Those lymphatic tubes take quite a beating; can hardly blame them for doing a bad job.

I've had oodles of blood tests. But no MD has ever asked for a sample taken from lymphatic tubes. Is a sample difficult to obtain? I don't know. But this is as far as I can go. I just hope I'll not be labeled a crackpot. What can be done to restore damaged lymphatic tubes? This may be impossible.



Milwaukee, Wisconsin

November 10, 1975

EVELYN SHADE  
Lyndon Station, Wisconsin

October 28, 1975

I am happy to hear there will be a hearing on improving services to arthritics. These services are readily available in cities, but to us in small communities it is very difficult to obtain help. The doctors are busy and don't seem to understand the pain and inconvenience arthritis brings to a person. If information on how to live with the disease could be easier to obtain to us, I believe it would be helpful.

I have had to quit my job, as I have arthritis in my hands and feet. I have had surgery on both thumb joints with implants. Many people don't know this surgery is available. It also is very expensive, but is a godsend. I still need more surgery if I am to go back to work. I was a cook in my own restaurant.

MRS VIOLA SPINNEY  
Hupertus, Wisconsin

October 30, 1975

Will do the best I can in writing a letter, would like to attend the meeting but don't know if I can.

I am 67 years of age and have arthritis very bad in the neck, which gives me some terrible headaches. I also have it at the tip of the spine, and besides that I have deterioration of the cushion of the spine.

Anybody who does not have arthritis does not know what pain we people go through. I ache going to bed and wake up aching.

I go to the doctor, but all he gives is pain pills, which kills the pain for a time and then it starts all over again. When you take pain pills so long it seems like they don't help anymore.

I sure would like to see a pill or medicine or an injection of some sort that could arrest the arthritis for sometime at least. Cortisone can be given, but I hear they leave some side effects, and I don't care for that.

I think the people who should articulate the things before the Commission would be:

- (1) Allied Health Professionals
- (2) People with arthritis
- (3) Elected officials

Wish you a lot of luck with your meeting.

H. STECHMESSER

My late wife died from arthritis. The years she suffered were many. Yet her life was extended due to a meeting we attended at MATC. The meeting dealt with the quacks. A short time later she placed herself under a doctor. I am very thankful for this meeting, for it accomplished many things for me.

I do regret that I have not been able to do more for the Arthritis Foundation. I do hope in the future I can do more.

ROBERT STRANDE  
Trevor, Wisconsin

October 21, 1975

Thank you for the invitation to attend the hearing. I plan on being there, and hope to bring a fellow sufferer.

In my case, arthritis seems to be part of the aging process. First angina pectoris, then arthritis, followed by removal of a cancerous kidney.

I am sixty-six years old and for the greater part of my life I was free of arthritis and its miseries, so I have been blessed. Also, it is not constant but arrives and departs suddenly and without apparent reason.

I was around fifty-five when it started bothering me in places other than my right knee. My neck would become taut and my head would be positioned properly for a good look at my left armpit. Three to seven days later it would leave just as suddenly as it had arrived. It was both painful and embarrassing.

When it appears in a shoulder or upper arm or both shoulders, it is difficult to even hold a cigarette. My ulnar nerves are pinched, but I don't know that this is part of arthritis.

When it appears in my left hip, it is as if a cord is binding me above the buttock and in the crotch, to circle the leg at its highest outer and inner limits. It also feels as if a rod is prodding me in the center of the buttock and pins are inserted in my frontal thigh.

I walk by favoring that leg during an attack, letting it swing while the other leg does the walking. This aggravates the right knee and when the pain in the left hip causes involuntary gasps and I break my stride, I sometimes fall.

This sharp intake of breath seldom affects my heart and this puzzles me.

Our bath is equipped with a grab bar and my usual remedy is to direct the shower spray on the affected area. I select areas where I apply oil of wintergreen and use a muffler around my neck on cold days.

Milwaukee, Wisconsin

November 10, 1975

My mother had arthritis in her toes and could scarcely stand a sheet on them. The joints of her hands were unsightly too. My father had it in his legs.

I feel the most urgent unmet need is for cars with higher tops to make access easier. Additional funds should be used to advertise your group.

ARLINDA SUDBRINK  
Sheboygan, Wisconsin

October 29, 1975

I am an arthritic--rheumatoid. It is a very special hell. At times I feel like being raked over with a red hot rake, tearing muscle, tendons & cords to shreds. Hands can't hold on to things anymore, are so painful as though smashed with a mallet. Knees, feet--out of shape. Barely able to get around.

We must find a cure for thiscrippler. No one knows what this is like except those that experience it.

Help! Help! Help!

MRS. LESTER SWEENEY  
West Allis, Wisconsin

October 28, 1975

I have rheumatoid arthritis. It started in 1953 and gradually progressed until (after using canes and crutches) I graduated to a wheelchair in 1964.

In 1967 I was in an automobile accident, breaking both arms and legs. My left knee cap was shattered and removed, both wrists are weak (the right one stiff), and the right ankle is crooked. My right leg is about two inches short because of the degeneration of the hip bone. Surgery has been suggested, but because of the practice of not putting in a prosthesis in a non-walking patient, I would be worse off than I am now.

In spite of hospitalization and medication I am getting worse. My hands are more crippled. It's high time that some solution be found to arrest or cure arthritis. Government grants are issued to study the love life of various insects and animals or why an aborigine sweats--who cares? We arthritics wish they would care about our problems.

On a local level I wish the Arthritis Foundation could provide a bus for the yearly meeting. I get the invitations but cannot accept.

National Commission, do your thing! Thank you.



Milwaukee, Wisconsin

November 10, 1975

CARL P. UNDERWOOD  
Whitewater, Wisconsin

October 24, 1975

As a member of the Arthritis Foundation of Wisconsin I am writing to you in regard to how arthritis has affected my life.

It has been nearly 40 years of constant endeavor to seek relief from the agonizing pains of this terrible disease.

It would take too long a letter to explain all the treatments and the amount of money spent to find someone that could treat arthritis and get results.

I have gone from one doctor to another, plus being in various hospitals and clinics, and have taken most all of the modern pain relievers, but nothing has helped. Fortunately I have no deformities.

I believe more research, better care, treatment, and lower cost would be of great help.

MRS. EVELYN S. WOREY  
Hayward, Wisconsin

I owe my arrested condition to Dr. Milton M. Bormen, only. More assistance and greater dissemination of information should be made available to the general practitioner at the grass roots level in America in handling arthritis. The populace in rural and outreach areas cannot afford or are not able to get to city specialists. The general attitude on the part of the patients and physician is painful apathy and helplessness. Our family doctors have only time limitations.

MRS. DONALD ROEBERGE  
Rice Lake, Wisconsin

October 24, 1975

At the invitation of the Arthritis Foundation of Wisconsin, I am taking this opportunity to make some comments as a person who has rheumatoid arthritis.

My R.A. was diagnosed when I was 34 years old and I am now (or will be, in just a few days) 43. I am married and have a 14-year-old son without whose help I could not manage, since I work full time as an office manager. A cleaning lady is another big help with the regular weekly house upkeep. There are still plenty of chores left for me!

After a synovectomy on my left knee three years ago, there was some improvement in that knee's function for a short time. I found it necessary to start using a crutch because of that knee about one year after the surgery, and have used it ever since. I am not convinced of the effectiveness of synovectomies and therefore rejected the recommendation to have this procedure done on my left wrist. It can "fuse" by itself, without surgery! If I were to see my rheumatologist today, I am sure,

after he had consulted with the orthopedic surgeon, they would advise synovectomies on both my right knee and right wrist.

There is too much ignorance concerning R.A. by the general public. A typical comment in my case is: "Why, you're too young to have arthritis! This is an 'old people's disease'." So educating the public about the different kinds of arthritis and who can have this problem (besides "old" people) is certainly a prime concern.

Another need is more physicians who are knowledgeable on the treatment and management of this problem. I have to go all the way up to the Duluth Clinic, which is quite an exhausting trip for me, to see a rheumatologist. This means that I don't go as often as I should. He does not ask me to see him every few months, so it has now been almost a year since I last had a talk with him. Surely this is not adequate management of a chronic disease! There is no one locally who would be of any assistance to me, medically. Is there any way for a specialist in a distant city to get your file to your local MD, so there would be someone nearby to see if a specific problem arose? The local MD should also be able to see you for routine checks between your visit to the specialist.

What is it like to have R.A.? It's a lot of HOPE...for a better tomorrow and a possible cure in your lifetime!

MRS. PEARL ZIOLKOWSKI  
South Milwaukee, Wisconsin

October 22, 1975

I am an arthritic for many years. I have to have a total hip replacement, for which I went on June 2 to Deaconness Hospital, and was scheduled to have surgery on the 4th of June, but due to the malpractice and the anesthesiologist, walked out on the 2nd of June. I was rejected. It put me in a state of depression, which took a long time to overcome.

I am on disability due to having one kidney; and it functions 50 percent. The right kidney was removed 21 years ago. I have high blood pressure, gout, sinus trouble, etc. I'm on so many drugs, it is not funny. But here is my main gripe:

There are so many things done for people with other afflictions like muscular dystrophy, March of Dimes, Heart Foundation, all other, like cancer-but we do not hear too much for arthritis patients. I guess you have to have it yourself to really know what it's all about.

I am on crutches and a cane at the present time--my spine is damaged. I have it in all parts of my body; my shoulder, elbows, ankles, wrist, fingers, toes--mostly damaged is the spine and hip. I wish that something could be done to help the UAF, so people would know more about it and how to take care of themselves.

It would be greatly appreciated if those afflicted with this terrible disease could lock up toward some help also. Thank you. We need your support. Don't you think it is high time something is done for people like us?

P.S. It is very hard for me to get out, so if I cannot make the meeting. I hope that there will be a nice group of people to help this cause. I hope I could make it.

MEMBERS OF AN ARTHRITIS CLASS  
Milwaukee, Wisconsin

October 27, 1975

We are members of an arthritic self-help class and have found it both interesting and helpful. It has motivated us to do more for ourselves. We wish others could have the opportunity to attend similar classes.

During a discussion of what we thought would benefit all arthritics most, these items took priority:

- (1) Increased emphasis on arthritis in medical schools.
- (2) More therapists trained to help arthritics.
- (3) Funding for treatments for those arthritics who would be helped by them but are unable to afford them.
- (4) More public information sessions on arthritis.
- (5) Continued research on arthritis.

It is our hope that by implementation of these and other ideas generated by arthritics themselves, someday there may be a measure of relief for the thousands of arthritics who are currently suffering the consequences of the disease. Members of an arthritis class:

Pearl Ziolkowski  
1842 Hickory Street  
South Milwaukee, Wisconsin 53172

Mrs. A. J. Hellen  
6260 S. Lake Drive, Apt. 718  
Cudahy, Wisconsin 53110

Helen Sitek  
5219 South Lake Drive  
Cudahay, Wisconsin 53110

Mrs. Irene Jojnacki  
2912 7th Avenue  
South Milwaukee, Wisconsin 53172

Mrs. E. Lynch  
1512 Menomonee Avenue  
South Milwaukee, Wisconsin 53172

Mrs. May Rolke  
613 Aspen Street  
South Milwaukee, Wisconsin

Mrs. Harold Frazier  
1304 Manistique Avenue  
South Milwaukee, Wisconsin 53172

Mrs. Lorette Wapp  
813 Lakeview Avenue  
South Milwaukee, Wisconsin 53172

Mrs. Marion Klcbuchar  
2710 E. Eaton Lane  
Cudahy, Wisconsin 53110

Mrs. Vernet Silowski  
1792 Poplar Avenue  
South Milwaukee, Wisconsin 53172





**RAMADA INN**  
**ST. LOUIS, MISSOURI**  
**November 11, 1975**







# TABLE OF CONTENTS

## CHRONOLOGICAL LIST OF WITNESSES ST. LOUIS, MISSOURI NOVEMBER 11, 1975

	<u>Page</u>
ROSS, Bernard A. President, Eastern Missouri Chapter, Arthritis Foundation	3-266
KELLY, Joseph F., Jr. Investment Banker; Past President, Eastern Missouri Chapter, Arthritis Foundation	3-267
RYAN, Michael Administrative Assistant to Senator Thomas Eagleton	3-268
BARDENHEIER, Virginia Mother of JRA Patient, Kirkwood, Missouri	3-269
BARDENHEIER, Kimberly Ann Patient, Kirkwood, Missouri	3-270
MEST, Debbie Patient, St. Louis, Missouri	3-270
STURDEVANT, Roger Treasurer, St. Louis Chapter, Lupus Erythematosus Foundation	3-271
GLOE, Darlene President, St. Louis Chapter, Lupus Erythematosus Foundation	3-273
ZUCKNER, Jack, M.D. Director, Arthritis Section, St. Louis School of Medicine	3-275
HERD, Kenneth, M.D. Chairman, Medical Advisory Committee, Nebraska Chapter, Arthritis Foundation	3-276
WALLER, Gordon, M.D. Executive Director and Clinic Administrator, Kansas City Chapter, Arthritis Foundation	3-281

	<u>Page</u>
HAHN, Bevra H., M.D. Co-Director, Arthritis Clinics, Washington University Medical Center	3-284
KUHLMAN, Robert E., M.D. Assistant Professor of Orthopedic Surgery, Washington University School of Medicine	3-290
AYLWARD, Dee, L.P.T. St. Louis, Missouri	3-291
LEOPOLD, Jane, M.D. Director of Information and Referral Services, United Way of Greater St. Louis	3-293
ORSCHELN, Don W. President, Orscheln Lever Sales Company	3-294
GAUNT, William, M.D. Clinical Director, University of Missouri - Columbia Arthritis Center	3-295
WELLS, John H., M.D. Kansas City, Missouri	3-297
ZEIDERS, Robert S., M.D. Central Illinois Chapter, Arthritis Foundation	3-298
WYNNE-ROBERTS, C. Rosales, M.D. Rheumatologist, Southern Illinois School of Medicine	3-299
PERKINS, Aline R. Mother of Patient, Chesterfield, Missouri	3-304
O'CONNOR, Dennis M., M.D. Cardinal Glennon Memorial Hospital	3-305
BOND, Christopher S. Governor of Missouri	3-307
CAREY, Margaret Supervisor, Services to Handicapped, Older Workers and Women, Missouri Division of Employment Security	3-308
SISK, Charles, M.D. Associate Professor of Medicine, Department of Medicine, Division of Immunology and Rheumatology, University of Missouri - Columbia School of Medicine	3-310

	<u>Page</u>
LAURIE, Gini Editor and Publisher, Rehabilitation Gazette	3-315
MC ALPIN, Bertha, R.N. Patient, St. Ann, Missouri	3-315
LIND, Reverend Ronald H. Deputy Commissioner for Senior Citizens, The Mayor's Office for Senior Citizens	3-316
WHITSON, S. William, Ph.D. Associate Professor, Department of Anatomy, Southern Illinois School of Dental Medicine	3-317
HESSER, Celeste Patient, St. Charles, Missouri	3-319
DORNER, Robert W., Ph.D. Assistant Professor of Biochemistry and Internal Medicine, Department of Internal Medicine, St. Louis University School of Medicine	3-320
MUENCH, Robert Patient, St. Louis, Missouri	3-322
MATYI, Elmer Patient, St. Louis, Missouri	3-323
DRY, Victoria Eastern District, Missouri Physical Therapy Association	3-326
HOLSTEN, Donna, M.S.P.H. Arthritis Patient Educator, Arthritis Center, University of Missouri - Columbia	3-327
TULL, Robert Secretary, Eastern Missouri Chapter, Arthritis Foundation	3-332
SCHENEWERK, Carla, O.T.R. Chief Occupational Therapist, Mount St. Rose Hospital	3-334
WESLEY, Sister Suzanne Sisters of St. Joseph Cardinal Ritter Institute	3-335



# SUBMITTED STATEMENTS

	<u>Page</u>
DAEHN, Emma St. Louis, Missouri	3-339
HILL, Carole Barnhart, Missouri	3-339
PERLMAN, Eugene St. Louis, Missouri	3-341
BROWN, James H. St. Louis, Missouri	3-342
BEAKLEY, Robert St. Louis, Missouri	3-343
VIETMEIER, Raymond H. St. Peters, Missouri	3-344
SCHARR, Adela R. Florissant, Missouri	3-345
ERGOVICH, Joseph Raytown, Missouri	3-348
SNELL, Jeanne St. Louis, Missouri	3-348
TRASTER, Mrs. Floyd Hopkins, Missouri	3-349
WATSON, Marcine Barnhard, Missouri	3-350
COUNTS, Grace Kansas City, Missouri	3-350
FERGUSON, John L., M.D. Springfield, Missouri	3-351
MINCHEW, Sara Brandon, Mississippi	3-352
NELSON, Hazel Kansas City, Missouri	3-352

	<u>Page</u>
RUDI, Milton H. Kansas City, Missouri	3-353
HESSER, Wayne M. Fairchild AFB, Washington	3-354
TINSLEY, Austin R. Poplar Bluff, Missouri	3-355
WARD, Harold Indianapolis, Indiana	3-359
EISBERG, Joe, R.Ph. Kansas City, Missouri	3-360
WHITE, Robert M. II Mexico, Missouri	3-362
SHULTZ, R. T., M.D. Oklahoma City, Oklahoma	3-363
MIKUS, Anita Florissant, Missouri	3-377
SMITH, Kenneth Kansas City, Missouri	3-378
BARNHART, Dorothy De Soto, Kansas	3-378
HAYES, Jim Maryville, Missouri	3-379
FORSTING, Marvel F. Florissant, Missouri	3-379
ISHAMS, Barbara G. Chesterfield, Missouri	3-379
ADAMS, Viola Kansas City, Missouri	3-380
BELANGER, Mary St. Louis, Missouri	3-380
CUMMINGS, Norman A., M.D. Louisville, Kentucky	3-381
ZELTWANGER, Mrs. Richard Wakarusa, Indiana	3-383

	<u>Page</u>
DAVIS, H. Scott Louisville, Kentucky	3-383
LEICHARDT, Hal St. Louis, Missouri	3-384
HULBERT, Bernard, M.D. St. Louis, Missouri	3-385
MORRIS, Alan D. St. Louis, Missouri	3-386
PERSON, Herman D., R.P.T. Peoria, Illinois	3-387
LEFFERT, Ann	3-387
KABERG, Frances M. Cedar Hill, Missouri	3-388
HOFFMAN, John C. St. Louis, Missouri	3-390
LIGHTFOOT, Georgia L. St. Louis, Missouri	3-390
ODEND'HAL, Nancy Columbia, Missouri	3-392
BREWER, Jeanne E. Kahoka, Missouri	3-394
ORF, Norbert W. and Mary C. Florissant, Missouri	3-395
MOON, Christine Cooper Fayette, Missouri	3-395
BAUMGARTNER Pacific, Missouri	3-396
BUGGS, Kathryn St. Louis, Missouri	3-396
DAVIS, Argus W. Overland, Missouri	3-397
WILLIAMS, Ida M. Kansas City, Missouri	3-397



	<u>Page</u>
DYE, Agnes Ozark, Missouri	3-398
ELDER, Nina Ferguson, Missouri	3-399
BAKER, Carol St. Charles, Missouri	3-399
SEARS, Ethel E. Lee's Summit, Missouri	3-399
MOORE, Edward E. St. Louis, Missouri	3-400
HILL, Alta B. Kansas City, Missouri	3-400
WYNN, Doris Skidmore, Missouri	3-401
WISS, Mrs. Bernard Kahoka, Missouri	3-401
THOMAS, Esther Palmyra, Missouri	3-401
HECKENDORN, Ray St. Louis, Missouri	3-402
COLONA, Anna	3-403
HAYES, Sandra Maryville, Missouri	3-403
HENLEY, Bernice C. Jefferson City, Missouri	3-405
COX, Amelia Shawnee Mission, Kansas	3-406
HENEHAN, Sister Mary St. Louis, Missouri	3-408
GILLESPIE, Alberta	3-408
BUERREMAN, Eliza M. Defiance, Missouri	3-409



P R O C E E D I N G S

ENGLEMAN: On behalf of the National Arthritis Act Commission, I welcome all of you to this public hearing of the National Arthritis Act. Before we start, I would like to ask the members of the Commission who are here to introduce themselves.

My name is Eph Engleman. I'm a practicing physician-rheumatologist in northern California and am attached to the University of California in San Francisco.

POLLEY: I'm Dr. Howard Polley of Rochester, Minnesota. I'm a rheumatologist on the staff of Mayo Medical School.

JENERICK: I'm Howard Jenerick. I'm a staff person at the National Institute of General Medical Sciences which is part of the National Institutes of Health.

LEWIS: I'm Vivian Lewis, former professor of kinesiology and physiology, Wilberforce, Ohio.

BATCHELOR: I'm Dr. Bill Batchelor. I'm with the National Institute of Arthritis Metabolism and Digestive Diseases. I'm currently serving as Executive Secretary to the Arthritis Commission.

SHIELDS: I'm a physical therapist representing the allied health professions on the Commission.

DONALDSON: I'm Dr. William Donaldson, an orthopedic surgeon from Pittsburgh, Pennsylvania.

SHARP: Dr. Gordon Sharp. I'm a rheumatologist at the University of Missouri in Columbia.

FELTS: Dr. William Felts, rheumatologist, Director of Rheumatology, George Washington University, Washington, D.C.

MELICH: I'm Doris Melich, President of the Utah Chapter of the Arthritis Foundation and a lay person on the Commission.

LAMONT-HAVERS: I'm Dr. Lamont-Havers, Deputy Director of the National Institutes of Health.

GAY: Dr. William Gay, Associate Director of the National Institute of Allergy and Infectious Diseases at the National Institutes of Health.

ENGLEMAN: Thank you, ladies and gentleman. All of you who are appearing as witnesses will be requested to announce your name, your title and organizational affiliation. In view of the very critical time constraints we must ask each witness to limit his comments to 3 minutes. Hopefully, this will permit questions and answers between the members of the Commission and the witnesses. I realize this is a very difficult requirement, but please do the best you can. We'll start now with Mr. Bernard Ross.



TESTIMONY OF  
BERNARD A. ROSS  
PRESIDENT, EASTERN MISSOURI CHAPTER  
ARTHRITIS FOUNDATION

ROSS: As president of the Eastern Missouri Chapter of The Arthritis Foundation, my concern is for the needs of more than 300,000 arthritis victims in a 73-county chapter area, much of which is rural but which includes the St. Louis metropolitan area and a number of other smaller population centers.

Within the chapter area we are fortunate to have three excellent medical schools: St. Louis University, the University of Missouri in Columbia, and Washington University, all of which have rheumatology programs. In fact, most of the rheumatologists in the chapter are affiliated with these institutions, providing expertise in clinical care and research as well as in professional education.

For the past 3 years, the Eastern Missouri Chapter, through funds made available by a large bequest, has been able to sponsor a fellowship program in the 3 universities, assisting in the training of 8 specialists in arthritis. Two are now in practice in the St. Louis area; another has joined the faculty of the University of Missouri in Columbia; of the others, one practices in another state and the remaining continue their training. This program has helped provide more specialists in arthritis, but the funds supporting it are now depleted and without additional sources of funds, the program will cease in July, 1975.

Who suffers from the critical shortage of arthritis specialists and professional training? One has only to answer the telephone at the Arthritis Foundation offices to hear daily of the many needs of arthritis sufferers. How would they benefit from the use of national funding of a long range professional education program?

First, the very increase in the number of rheumatologists trained would provide expertise, not only in eastern Missouri but nationally, for the differential diagnosis and complete treatment plan needed by outpatients. It would also provide medical educators to staff rheumatology programs in the numerous medical schools now lacking professional education in arthritis.

Secondly, perhaps more important than the training of more specialists is the upgrading of professional education of primary care physicians. Most arthritis patients, particularly those in rural areas, will most likely continue to be treated by their own family physicians, remaining in their own communities for all but the most specialized care. It is of the utmost importance that all our physicians, including those already in practice, become more familiar with the broad range of rheumatic diseases and the special resources available for complex cases.

Third, the increase in clinical care at the professional training institutions would serve the interests of both the professional training program and the patient. It would seem reasonable to assume that the number of patients treated and the quality of treatment would both

increase in proportion to the number of physicians being trained in rheumatic diseases.

Fourth, the establishment of auxiliary programs in the allied health fields would be a natural outgrowth of the basic professional training programs in the comprehensive treatment of arthritis. The complete rehabilitation of the arthritic through every means possible should be our goal.

Finally, in local medical institutions, research both basic and clinical is pursued as a means to the end we all seek--the only hope for so many victims of the cruel rheumatic diseases: a cure.

To support, through the further development of professional education in Missouri, the complete program of education, care and research espoused by the Arthritis Foundation, is, I believe, to focus our attention on the one reason for our being here today: the arthritis patients of today and the potential arthritis victims in all of us.

ENGLEMAN: Thank you, Mr. Ross. We'll go on now to Mr. Kelly.

TESTIMONY OF  
JOSEPH F. KELLY, JR.  
INVESTMENT BANKER  
PAST PRESIDENT, EASTERN MISSOURI CHAPTER  
ARTHRITIS FOUNDATION

KELLY: In 1955 the multiplicity of problems faced by the millions of victims of arthritis in the United States was dramatically brought to my attention.

Since then I have been active as a volunteer in fighting to find the cause and cure of this most crippling and painful disease.

I have served locally as President of the Eastern Missouri Chapter of the Arthritis Foundation and for 10 years I served as a director of the national, representing the arthritics of 7 states.

Therefore, I feel well qualified to appeal to the legislators of this great country to put forth their best efforts and a sufficient amount of money to help stamp out this disease.

I will not bore you with all the facts and figures that have been compiled, I am sure you are well aware of the staggering cost to business and government, in lost time from work, medication and treatment and, unfortunately for the victims, the quackery that milks hundreds of millions of dollars from the desperate suffering public.

You will receive thousands of pleas for help to fund a program to find the cause and cure of arthritis. I firmly believe the citizens of this country have the right to demand that the legislators provide the necessary money to carry out the National Arthritis Act.

ENGLEMAN: Thank you very much, Mr. Kelly. Mr. Kelly is an old friend of many of us sitting here. He was on the national board of the Arthritis Foundation for many years. We're glad to see you again. We'll go on now to Michael Ryan.

TESTIMONY OF  
MICHAEL RYAN  
ADMINISTRATIVE ASSISTANT TO  
SENATOR THOMAS EAGLETON

RYAN: I am assistant to Senator Thomas F. Eagleton. I first of all would like to bring regrets of Senator Eagleton that he could not personally attend. The Senator is very concerned with this problem. In fact he was one of the sponsors of the National Arthritis Act that was signed into law this January.

The Senator asked me to attend basically to listen. I did not know I was going to testify before such an august body. But I do want to let you know that the House and Senate Appropriations Committees have now acted to implement this Act. There is a difference in the amount of funding that they requested, but the difference is on the positive side. The administration requested a funding level at \$100.4 million, and the House appropriated funds to the tune of \$173.9 million, and the Senate \$176.9. It is now in Conference Committee and generally the Conference Committee will come out with a report somewhere between the two figures. Other than that I will be listening to the testimony of the other witness.

ENGLEMAN: We are very delighted to hear that Senator Eagleton is for the Arthritis Act. May I ask you, these figures, \$100 and some odd million--appropriations for what?

RYAN: These are the figures for the National Institute of Arthritis Metabolism and Digestive Diseases, and the breakout, I take it, occurs at a later point--what goes where.

ENGLEMAN: Yes, but I must remind our audience that this is entirely exclusive of funding of the National Arthritis Act. As yet, we have no appropriations for the implementation of the act itself. But I am delighted to hear that Senator Eagleton will support the appropriations.

Any question from a member of the Commission?

MELICH: I would like to urge everyone here to follow Senator Eagleton's example and write your congressman and tell him you are really interested in helping us pass this Bill.

RYAN: People who are interested in this problem are very prolific in their writing and it is a very important thing. I would second your motion.

ENGLEMAN: That's very reassuring.



VOICE: I wonder if I could ask Mr. Ross what was the dollar figure that was necessary to support the fellowships in rheumatology colleges?

ROSS: Right now, we are using a \$12,000-a-year figure. I think it would be approaching \$13,000 by 1976.

VOICE: That was per fellow.

ROSS: Per fellow, per year.

ENGLEMAN: Thank you very much, gentleman. May we ask the Bardenheier family to come forward please.

TESTIMONY OF  
VIRGINIA BARDENHEIER  
MOTHER OF JRA PATIENT  
KIRKWOOD, MISSOURI

BARDENHEIER: I would like to speak as a parent of a child with juvenile rheumatoid arthritis and as a member of a parents' group formed for parents like myself in eastern Missouri. During our meetings we have discussed many of the problems that we face as parents of children who suffer daily from the devastating effects of this disease.

One of the most common problems we have found is getting a quick and proper diagnosis for these children. Many children and their parents have lived through months of pain and fear, going from one doctor to another, trying to find the answer. For some of them the search went on for years. We are in desperate need of further education for our pediatricians and other physicians so that the children can be diagnosed quickly, and proper treatment can begin. We are also desperately in need of physicians who specialize in rheumatology. Therefore we need to encourage and support those who wish to go into this field.

Once the children are diagnosed, we naturally, as parents, want to know what will happen to our children. Of course the answer is always the same--we do not know if he will become deformed. We do not know if it will go away. We do not know if the medication will help.

So we think maybe it will go away, maybe it will not. Maybe he will be able to walk next week. Maybe the pain will stop and he will sleep tonight. Maybe surgery can correct some of the deformities. Maybe he will be able to lead a productive life; I should be saying she because I have a daughter who has had JRA since she was 2 years old and those are an awful lot of maybes for a 10-year-old child and her family to live with.

Our only hope is to find the answers to all the unanswered questions concerning arthritis. Please consider the importance of research to our children and their future.

TESTIMONY OF  
KIMBERLY ANN BARDENHEIER  
PATIENT, KIRKWOOD, MISSOURI

BARDENHEIER: I think that the country needs more swimming programs for the children so that they may have the privilege of learning to swim as well as others without arthritis.

I, as a victim of arthritis, know what it is like to have arthritis. It can be very painful at times. It also means having to take pills and medicines. I am 10 years old and have taken many medicines in my life; many of them were pills and some liquids. Some of the children must go to the hospital. Even they cannot do anything to stop the great pain that they have.

I really feel bad about those children that have it bad. It may strike you. So I hope that after all this you will help so we can find a cure for them.

ENGLEMAN: Thank you very much, Kimberly. I think that before we ask Mrs. Bardenheier some questions, we should proceed to hear from another patient, Debbie Mest.

TESTIMONY OF  
DEBBIE MEST  
PATIENT, ST. LOUIS, MISSOURI

MEST: On January of 1973, when I was in eighth grade and 13 years of age, I became very ill; also I had flu symptoms. No one knew what was causing my illness. We went from doctor to doctor trying to find out what was wrong with me. We finally went to Dr. Gerst when I was unable to get around by myself, and through tests, he found out I had rheumatoid arthritis. The first 3 months I was unable to get off the couch, as I could not walk, feed myself or anything like normal. My family helped me in several ways. About the month of April, I advanced to crutches; after that I gradually was able to walk.

Since I lost a whole semester of school I was tutored at home by a teacher provided by our school district. I studied and passed eighth grade and received my diploma. I was a Girl Scout and I am now a Senior Girl Scout. During my illness I had time to work on my first class award and completed it in 1 year, which normally takes 2 years. Since I could not do much of anything I did my research. My leader came to my home to help me pass this award. It is an honor to earn such an award.

I missed a lot of school events and was not able to participate too much with activities upon my return to school in September. The year was really a hardship on my parents, two brothers and a sister. I am the third oldest.

For 1 year I was on Pentid 400, four times a day, at first, then Pentid 250. Just recently I had a small flareup which made me miss 1 week of school. Now it is November and I am feeling pretty well. At times I

still have a stiffness and swelling in my right knee and my feet. Aspirin helps sometimes.

The cost to my parents was tremendous, I know, as most of this is not covered by medical insurance. My hopes are high for a cure as I know that polio was a threat many years back and they have found a cure for that. My future? Time will tell. I must take life as it comes. Donations for research are greatly needed.

ENGLEMAN: Thank you very much, Debbie. I think that it will be reassuring to the Bardenheiers and to Debbie to know that provisions of the National Arthritis Act are directed toward children with arthritis, in terms of actual patient care and also research. Are there any questions from the members of the panel? If not, we will call on another patient, Roger Sturdevant.

TESTIMONY OF  
ROGER STURDEVANT  
TREASURER, ST. LOUIS CHAPTER  
LUPUS ERYTHEMATOSUS FOUNDATION

STURDEVANT: Ladies and gentlemen:

My name is Roger Sturdevant. I am the cofounder and treasurer of the Lupus Erythematosus Foundation, Missouri, St. Louis Chapter. I am also the chairman of a steering committee made up of laymen, doctors, and lawyers who are forming a national lupus foundation in the United States.

I am here to address you in the name of lupus erythematosus, a member of the collagen family of diseases. This is a disease that affects and becomes known to thousands of persons a year, causing crippling and death. Approximately 5,000 persons die each year of this disease and it is felt that over 1/2 million persons are afflicted with SLE.

This disease (lupus) is very perplexing, for doctors as well as patients. There has been little research done in this field. The research in arthritis and lupus is very far behind other diseases of the same magnitude.

This past week we met in Boston, Massachusetts and I am very hopeful that a national lupus foundation will be formed within the next few months. There are so many problems connected with lupus that most persons are felt to be hypochondriacs before they are diagnosed as having lupus. So many parts of the body can be affected at one time or separately that it is hard to detect. Some lupus patients have died showing negative lupus results on tests, and then the autopsy shows death caused by lupus. True, mostly women in the childbearing years are afflicted with this disease; however, there is a percentage of men also. Lupus has no regard for sex, age, or race. Very few persons afflicted with lupus (systemic) are able to hold a job, steady or part-time. We are unable to go for any length of time without getting overly tired, and we tend to fall to pieces under very little strain.



Strain usually causes a flareup. Also, very few of us can be out in the sun for any length of time. This is very hard, emotionally, on the patient and the families as most of us do like some outside activity.

The major problem with lupus is the fact that most patients tend to look fairly normal and healthy on the outside. You must understand that in layman's terms we literally fall apart and die from within. The chances for survival have increased over the years due to the advance in medicines. At that time the patient was told 1 year. Now its felt to be around 7 years. Knowing there are exceptions to this just as there is in anything, some of us have passed this mark and, needless to say, we are very happy about it. I, as well as members in our lupus chapter, feel that with additional monies allotted for the research of lupus it will give us a better chance as well as those that come after us. Lupus and arthritis are very close and almost run hand in hand, but we do need separate monies for separate research. Until lupus is conquered there will be thousands of persons suffering, paying astronomical medical bills, causing undue hardships on patient and family. Also many breadwinners without work are on welfare, both State and Federal. Most companies and corporations do not want to hire anyone with arthritis or a terminal disease such as lupus. This is very hard for an individual to cope with, especially a person supporting a family. It is degrading and a mental torture.

Lupus must be given a chance to be heard. We need research money as well as the Arthritis Foundation for research. We all hope that one day working hand-in-hand, yet separately, at the medial profession will come up with a cure for both of these baffling, dreaded diseases.

It is my wish, desire and prayer that Federal funding can come to both the Arthritis and Lupus Foundations to ease the pain and suffering that, combined, reaches millicns of persons around the world daily. I know as one how wonderful it would be to get up in the morning, just once, without pain and hope that I could be free of pain if only for a few hours. Wouldn't this be wonderful?

I plead with you in the name of all who suffer with arthritis and lupus to keep an unbiased mind and return to Congress and plead our cause. Thank You.

ENGLEMAN: Thank you, Mr. Sturdevant. Your testimony reminds us here on the platfcrm as well as those in the audience that there are at least 50 types of arthritis and that lupus is one. We heard previously from the young ladies who had juvenile rheumatoid arthritis. This is another example of arthritis. Before we ask for questions from the Commission we will call on Darlene Gloe.

TESTIMONY OF  
DARLENE GLOE  
PRESIDENT, ST. LOUIS CHAPTER  
LUPUS ERYTHEMATOSUS FOUNDATION

GLOE: I am more than glad to testify before the National Arthritis Commission. I am a young housewife who was diagnosed as having systemic lupus erythematosus 3 years ago. Ninety-five percent of lupus sufferers have arthritis. I have suffered for 3 years now. The medication has helped and I have felt better since I have accepted it.

At the time I was diagnosed, I called and talked with doctors, many of whom had had only one case of lupus and did not want to take my case. I searched for a year and a half to find a doctor who was doing research in lupus and could understand what I, as a patient, was going through.

There are around 4 to 6,000 new cases each year, and an estimated 500,000 people in the United States with lupus. There are many people out there still searching for the right doctor. Almost all written material at libraries is outdated. It terrifies those who do not know. Why don't they know?

The answer is simple. There are not enough informed physicians who are aware of the problems; maybe a handful in a community know how to detect lupus and how to understand our problems.

I believe there should be more information about the disease available in lay terms to the afflicted. The public libraries are very outdated, I believe material should be given to them, the literature that may help the patient, family, doctor and friends. We need something to read that will give us confidence that research is progressing at a rapid rate to find the cause and cure for this disorder.

I think it would be beneficial for all if more physicians entered the field of rheumatology and more physicians trained in rheumatology would teach at the medical centers so that the general practitioners and internists would be well acquainted with systemic lupus erythematosus.

I believe there should be treatment centers set up with trained doctors who understand what the patient goes through, literature available there, family counseling, trained personnel who will go to the home if necessary to help the family and patient. I would like to see more research done in the area of medication. As anyone knows, steroids are a God's blessing, but the side effects are like adding one problem to another.

The National Arthritis Act, signed by President Ford last January, gave us much hope. We believe if a cure is found for arthritis, lupus or another collagen disease, there will be a cure for all.

When I say we, I mean the members of the Lupus Erythematosus Foundation of Missouri, St. Louis Chapter. I am the president of this foundation and have seen so much of the suffering, the misery the people go through finding a doctor, and then maybe to find out he is not aware of

lupus, and the struggle continues until a trained physician is found. Also, the need for information is so great. I spend many hours on the phone just trying to reassure people, as there is little material at hand.

I hope the money will go to the training of doctors, material made available, more research in the way of drugs, trained personnel who can help families of patients with lupus and related diseases, treatment centers, and last, but not least, the cause and most important the CURE for lupus erythematosus and its related diseases.

ENGLEMAN: Thank you, Ms. Gloe. Are there any questions from the members of the Commission?

VOICE: May I ask Mrs. Bardenheier, I think you said that you belong to a parents' group for juvenile arthritis. How was that formed?

BARDENHEIER: With the help of the Arthritis Foundation. One of the women got the parents together and slowly but surely we are building up a group.

VOICE: How big is your group?

BARDENHEIER: Well, each meeting we have different parents show up. It is very hard to get all these people together. Altogether I would say we have about 30 or 40 parents.

VOICE: How long have you been going?

BARDENHEIER: It has been about 2 years.

VOICE: Mr. Bardenheier and Mr. Sturdevant, I do not intend to frame this in a personal context, but I have not heard any of you specifically address the problem of financing of medical care in your involvements community wide and nation wide. Have you identified a problem relating to individual financing or insurance policies, as they are now issued, adequate for the experiences that you have encountered?

BARDENHEIER: I do not really believe they are and I don't see how anything could be. It has really been very rough on us and many of the parents in the group. It has really financially drained us for 7 or 8 years.

STURDEVANT: My name is Roger Sturdevant. I have been on social security disability for approximately 3 years and over the past 10 years, I have paid out more than \$60,000 above insurance. This was related on my income taxes, and I've been checked several times because that is quite an astronomical figure.

We have approximately 275 people on our mailing list in our lupus chapter and well, as for myself, my medical bills, just on the medication alone, run approximately, \$100 a month. And I enter the hospital about twice a year and, over the past few years, I have had 14 major operations. So medical is very high and most of us are in the red, because insurance just does not cover enough of it.



VOICE: You are saying perhaps that, once the diagnosis has been made, you are unable to obtain major medical coverage.

STURDEVANT: Yes, sir. Nobody will cover you. When I was actively working as a manufacturer's representative, I was carrying a major medical policy. When they let me go because of my health, I was put on just a family coverage. And I went from just \$9 a month to \$112 a month for coverage. And instead of major medical, all it provides is \$50 a day in the hospital and no outpatient care and a maximum \$600 on operations. It covers no medications.

SHARP: I would like to ask Debbie or Kim if there is anyone in your school, any of your teachers or nurses, or anyone else who has been talking to you about arthritis or any other health problems, or do you feel that your classmates and your teachers understand your problems?

DEBBIE: No one really talks at the school, but I feel that they know how research is needed for arthritis.

ENGLEMAN: Thank you very much. We will now call on a group of physicians, Drs. Zuckman, Hahn, Herd, and Waller. And Kuhlman, Dr. Robert Kuhlman.

TESTIMONY OF  
JACK ZUCKNER, M.D.  
DIRECTOR, ARTHRITIS SECTION  
ST. LOUIS SCHOOL OF MEDICINE

ZUCKNER: I am Dr. Jack Zuckner. I am director of the arthritis section at the St. Louis School of Medicine and a professor of medicine. There are so many things that can be said, some of them very obvious: the great need for more research and so forth. What I would like to do is to stress some other features which I do not believe have been stressed sufficiently in the past.

- (1) There is a great need for training of clinical rheumatologists who will practice rheumatology afterwards. Unfortunately, such fellowships for such individuals are almost nonexistent. Monies to support this type of fellowship are rarely available, especially at the national level.
- (2) I would think it best to decentralize some of the funding for fellowships and grants because smaller institutions are frequently not supported adequately. The general lack of monies for arthritis purposes has necessitated that most of the finances go to the few leading insitutions in the country; this apparently has been the policy of the Arthritis Foundation and other granting agencies. Although this has been necessary to a great extent, I believe it has led to a definite neglect of the total arthritis picture.
- (3) In conjunction with the above, I would suggest that local chapters of the Arthritis Foundation have control of some of the

funding for fellowships and other types of arthritis support for institutions that are in their areas. The local chapters of the Arthritis Foundation have a better understanding of problems in their community. Without the support of the local Arthritis Foundation chapter in the St. Louis area, some of us would not have been able to function in terms of many services, including fellowships, patient care, layman and professional education, and research. Grant you, I am not saying that this should be the total means of distribution, I mean it should be one of the ways and should be distributed with regard to the proper total arthritis picture in this country.

- (4) More care for the arthritis patient in rural communities in conjunction with more education for the local physician is essential. Support for establishing consultation teams, other required personnel, and facilities for treating patients in rural areas would be necessary for such a program.

ENGLEMAN: Thank you, Dr. Zuckner. May we proceed to Dr. Herd?

SUBMITTED STATEMENT OF  
KENNETH HERD, M.D.  
CHAIRMAN, MEDICAL ADVISORY COMMITTEE  
NEBRASKA CHAPTER, ARTHRITIS FOUNDATION

Dr. Engleman and distinguished members of the Commission:

I am a pediatrician and rheumatologist, presently employed as an associate professor of pediatrics at the Creighton University School of Medicine in Omaha, Nebraska. Since I am one of four fellowship-trained rheumatologists and the only full-time academic rheumatologist in the State of Nebraska at either of its two medical schools, and because of my role as Chairman of the Medical Advisory Committee of the Nebraska Chapter of the Arthritis Foundation, I can reasonably speak to you on behalf of the needs of both universities as well as the professional practitioner needs of the "community" of Nebraska. My training in rheumatology as a Postdoctoral Fellow of the Arthritis and Rheumatism Foundation was under the guidance of Drs. Ralph Jacox and John Vaughan at one of this country's first five Arthritis Research Study Centers at the University of Rochester in Rochester, New York. Several of my associates in training at that institution have made outstanding contributions to rheumatology and their names are well known to you: Dr. Eugene Barnett, Dr. Vincent Butler, Dr. Edward Mongan, Dr. John Condemmi, Dr. Jerry Gleich, Dr. Eugene Hunder, and Dr. John Leddy. My current areas of interest are the infectious etiology of JRA and treatment of the mucopolysaccharide storage diseases.

My personal contributions to the field of rheumatology have been the following:

- (1) Demonstration of live rubella virus in vaccine-induced rubella arthritis.
- (2) Aggravation of JRA by "superinfection" with rubella virus.



- (3) The effectiveness of hyaluronidase as a corrective factor for cultured Hurler fibroblasts.
- (4) The effectiveness of hyaluronidase in the treatment of patients with Type I and II mucopolysaccharide storage disease.

In recent years I have taken a vigorous interest in Federal matters concerning support for rheumatology. This is attested to by letters to President Nixon concerning withdrawal of NIH Traineeship programs and correspondence with appropriate senators and representatives concerning passage of the National Arthritis Act (PL93-640).

Our situation is as follows: With a population of about 15 million (including approximately 85,000 residents in Council Bluffs, Iowa) we have an estimated arthritic population of 130,000 victims in the State of Nebraska. There are 1,990 practicing licensed physicians in the State, 384 resident physicians in training, and 865 medical students in the combined two medical schools. When I arrived at Creighton 3 years ago the rheumatology needs of both medical schools were met by one full-time academic internist-rheumatologist. He has since left to take a position at another university. During his 5-year stay in Omaha he developed two arthritis clinics at both medical centers. There are in addition three board certified internist-rheumatologists practicing in Lincoln, Nebraska, the State capitol with a population of 150,000 people about 60 miles away. Two of these men have long assumed a part-time role in the education in rheumatology at one of the medical schools.

Since the departure of the previous academic rheumatologist, the arthritis clinics at both institutions have been reduced to half a day a week. One of them is staffed part-time by one of the rheumatologists from Lincoln. The arthritis clinic at the other institution is now staffed by an academic internist who has had exposure to rheumatology but no formal training in that discipline. The two rheumatologists practicing in Lincoln have taken on an increased load of students and residents in an elective rotation in rheumatology. One school still has a half day a week pediatric arthritis clinic. Thus, at neither school is rheumatology adequately taught. There are no rheumatologists on call on the premises for consultation. There is no concentrated teaching program in rheumatology. There is no continuity of patient care with supervision by a rheumatologist. There is no continuity in the teaching of rheumatology. In essence, the teaching of rheumatology occurs in bits and pieces--by fragmented happenstance!

Considerable expertise exists in many disciplines of vital support to good rheumatology. Immunology and clinical allergy is very strong with expertise for the study of T and B cells in the laboratory of Dr. E. Chaperson, a former associate of Dr. Henry Claman in the original description of T and B cells. Orthopedics is developing at both schools with recently appointed new full-time academic chairmen who are planning residency programs. Both chairmen have expressed strong interest in rheumatology; one already devotes time to my Medical Advisory Committee for the Arthritis Foundation. The basic laboratory support for clinical rheumatology is available in clinical pathology at both institutions, with the exception of polarizing microscopy for joint fluid crystallography.



Pathology, well represented at both schools, is particularly strong in immunopathology at the Creighton University School of Medicine under the direction of Dr. Wadi Bardawil, one of the original discoverers of the antinuclear factor in systemic lupus erythematosus.

Departments of radiology are excellent at both schools with full isotope capability plus technical skill in arthrography, ultrasound, and xerography. Ophthalmology has a strong residency program at the University of Nebraska. Otolaryngology at Creighton is developing a vigorous new program in the form of a Speech, Hearing and Communications Disorder Institute generously supported by an endowment from Boy's Town. Genetics is well represented by Dr. Henry Lynch's group at Creighton investigating cancer genetics and by Dr. Terry Myer's National Foundation-sponsored clinical Genetics Evaluation Unit serving pediatrics at both institutions from its base at the Children's Hospital. Biochemistry of the mucopolysaccharides of connective tissues is represented by myself as well as one of the biochemistry faculty staff at Creighton. Microbiology has outstanding leadership in Dr. Eugene Sanders and several of his former associates at the University of Gainesville who are now located at both medical schools in Omaha. Thus, there is depth of talent in all the related disciplines, but no concerted effort in channeling these forces on behalf of rheumatology.

I have depicted our needs in the "community" of Nebraska for patient care and education. The need is great. Perhaps it is best exemplified by a comment I recently overheard at a 3-day medical society meeting attended by some 600 practicing physicians in Omaha. As he approached the arthritis display booth among the many exhibits in the hall, one physician nudged his companion, leaned over, and said, "Gee, there's the worst disease I treat from day to day and what are they telling me to do about it?" I was pleased to see that he diligently attended two lectures given by Dr. Gene Hunder from the Mayo Clinic. But the needs of that doctor and the hundreds of other doctors in the small communities of Nebraska for guidance in the treatment of arthritic patients cannot be met by one or two lectures a year by visiting rheumatologists!

I believe the needs of our "community" can best be met by the establishment of an arthritis center under the dual sponsorship of the two university medical schools. Although this proposal is that of one man, it is favored by the Executive Board of Nebraska Chapter of the Arthritis Foundation as previously reported to you in writing by the Chapter President, Mrs. Cwen Sadler, and the Executive Director, Mr. Richard Paulson on October 28 in Denver, Colorado. Thus, I propose an arthritis center, not for one, but for two medical schools. The Commission might wonder whether such a center would equally serve both universities and avoid unfair division of services. I hasten to assure you that wiser heads have prevailed in Omaha by the formation of a cooperative organ between the two schools in the form of the "Creighton-Nebraska University Health Foundation," a body composed of the medical deans, the vice presidents for health science, and one trustee from each university, plus the senior executive officer of the county medical society. As the need arises the foundation also has its own legal counsel. Furthermore, the precedent for functions serving both schools has been set by the prior establishment of two subspecialty board-approved residency programs

sponsored jointly by both schools, one in neurology and one in dermatology. Further evidence of interest in rheumatology on the part of both schools is borne out by a firm verbal commitment to me by the chairmen of medicine that there are already line dollars for salary for at least one position in full-time academic rheumatology at each medical school.

To more adequately serve our needs in rheumatology, I propose an arthritis center jointly sponsored as described above with four fully trained internist-rheumatologists besides myself. At least three of these should be full-time academicians. Supporting personnel should include secretaries, physical therapists, social workers, nurses, occupational therapists. Each school must be represented by at least the following professional persons: an internist-rheumatologist, an orthopedic surgeon, a physical therapist, and a pathologist and psychiatrist with heavy commitments to rheumatology at the center. Additional depth must be represented by a pediatric rheumatologist, an immunologist, a virologist-microbiologist, a neurologist, an ophthalmologist and a dermatologist--all with a heavy commitment to rheumatology at the center, but coming from either school. The program should also include provisions for two clinical fellows or trainees and one or two fellows devoted to bench work type research.

The center I propose would adequately serve the entire community of Nebraska as a place of referral for the arthritic patients in this area. It would further serve the educational needs of the physicians in training. Correspondence received from Dr. George Webster, Director of Evaluation of the American Board of Internal Medicine, indicated that approximately 15 percent of internal medicine board examination questions pertain to rheumatology. A smaller percent, less than 5, pertain to rheumatology in pediatric boards. The center would serve these educational needs. Furthermore, there is an increasing emphasis, countrywide, on the training of primary care physicians. This is particularly true in the Nebraska medical schools where family practice training programs are by far the largest. The center would serve the training needs of these physicians, both at the resident level by inservice programs, and at the practitioner level by continuing education programs in depth.

The above depicted arthritis center is but a preliminary sketchy outline. My Medical Advisory Committee staffed by the previously mentioned three internist-rheumatologists, as well as by five other medical faculty drawn equally from both universities, are devoting time to the further drafting of formal proposals for such a center. We know that Federal dollars for the development of such a center will attract dollars from private donations on the local scene. Preliminary sorties in this direction have already been made. Although I speak to you as one individual, the ideas put forward here have been informally expressed to the Creighton-Nebraska University Health Foundation where they have been warmly received.

Ladies and gentlemen of the Commission, community needs of the State of Nebraska in its attack on arthritis can best be met by the



establishment of a dual university arthritis center and I urge this form of commitment for dollars budgeted under the National Arthritis Act.

TESTIMONY OF  
KENNETH HERD, M.D.

HERD: Dr. Engleman and members of the Commission:

I am a pediatrician-rheumatologist. I speak to you on behalf of the medical care needs of 130,000 arthritis victims, the consultative needs of 1,990 practicing licensed physicians, the postgraduate educational needs of 384 young physicians in residency training programs, and the basic graduate educational needs of 865 medical students, all in the State of Nebraska. Today, these multiple needs are met by three board certified internist-rheumatologists and one pediatric rheumatologist. However, the distribution is unbalanced, the three internist-rheumatologists are devoted to the practice of rheumatology in Lincoln, Nebraska with a population of 150,000 people. They contribute, on a part-time basis, to the educational needs of the two medical schools and will continue to do so. The pediatric rheumatologist is the sole, full-time academic rheumatologist at either school. The two schools, Creighton University and the University of Nebraska Medical Center, are located in Omaha, serving a population of nearly 600,000 people.

The above noted needs can best be met by the establishment of a single arthritis center in Omaha sponsored and staffed equally by both medical schools. The mechanism for establishing such a cooperative center between these two schools exists in the form of the Creighton-Nebraska University Health Foundation composed of the medical deans, the Vice Presidents for Health Sciences, and one trustee from each university plus the senior executive of the county medical society. The precedent has been set by the previous establishment of two subspecialty board-approved residency programs sponsored jointly by the two schools, one in neurology and one in dermatology.

Between the two schools we presently have depth in all the necessary supporting services for such a center. Both schools have excellent departments of radiology with the latest techniques including full isotope capability, arthrography, ultrasound and xerography techniques. Both schools have newly appointed full-time academic chairmen in orthopedic surgery, both with a personally expressed keen interest in rheumatology. The University of Nebraska has a full-time academic chairman of ophthalmology with an approved residency program. Pathology at Creighton is highlighted by the recent addition of several new young immunopathologists and electron microscopists headed by Dr. Wadi Bardawil, one of the original independent discoverers of the antinuclear antibody in lupus erythematosus.

Ladies and gentlemen, it is all there but the rheumatologists. One pediatric rheumatologist cannot begin to meet the educational need in rheumatology at two medical schools.



I envision a dual university arthritis center staffed by five rheumatologists; a center for exemplary care and excellence in teaching; a center to attract new young minds and bodies eager for careers in rheumatology; a referral center for the complicated case refractory to present treatment; a center for the training of primary care physicians, heavily emphasized in today's large family practice residency programs in our state.

My Medical Advisory Committee, staffed by the above-mentioned internistrheumatologists and by medical faculty drawn equally from both schools, are devoting increasing time to the drafting of formal proposals for such a center. I will need your financial support and urge this form of expenditure of Federally budgeted dollars from the National Arthritis Act. Thank You.

ENGLEMAN: Thank you, Dr. Herd. We will now call on Dr. Waller.

TESTIMONY OF  
GORDON WALLER, M.D.  
EXECUTIVE DIRECTOR AND CLINIC ADMINISTRATOR  
KANSAS CITY CHAPTER, ARTHRITIS FOUNDATION

WALLER: I believe that a short word of comment is in order regarding the clinic operated by the Kansas City Chapter, which is in itself a novel type of experience not usually associated with a chapter.

I. PREFACE AND HISTORY

The clinic stemmed from the interest of one individual, Dr. C. Stewart Gillmor, a physician in Kansas City who became interested in the disease in the late 30's and who traveled to England and Ireland to obtain information and further his studies of the disease. Dr. Gillmor brought back to this country and to Kansas City specific ideas for the establishment of departments of medicine for the control and ultimate cure of the disease, which at that time was highly recognized as the problem that we now only attest to and admit in evidence.

Dr. Gillmor worked hard, was instrumental in helping to establish the national foundation, was one of its early leaders and was an associate of Dr. Hench in development of cortisone. His writings and conclusions are available to me and from which I and my directors, prior to my association with the foundation, have directed their program activities toward the fulfillment of his recommendations as set forth some 20 to 25 years ago. Strangely enough, we see by comparison how closely they resemble, almost to the wording, some of the very conclusions as set forth in the Arthritis Act, with certain minor differences as to procedure, but not as to intent and ultimate goal.

Regretably Dr. Gillmor died in the early 60's, shortly after he personally raised the funds and supervised the construction of the building that still houses our clinic. Therefore, I am submitting the following outline of the various recommendations of the Kansas City chapter for the implementation of the Arthritis Act in order that it be

successful and according to the original proposals as set forth and by experience as accumulated in 27 years of the operation of the diagnostic clinic in greater Kansas City, Missouri.

## II. STATISTICAL VALUES DRAWN FROM KANSAS CITY DIAGNOSTIC CLINIC

- A. From 1948, when Dr. Gillmor began his program of teaching and care, his work was primarily within the scope of the major medical community, specifically the general hospital and other medical institutions.
- B. Beginning in the early 60's, Dr. Gillmor and the board concluded that an arthritis program, as they foresaw its ultimate development, could not be accomplished within the established medical system.

Unfortunately, the foundation has found by experience that programs of education developed by major medical institutions are not generally developed on the basis of patient need, but rather as to what may be politically and financially expedient.

Therefore, you find a disease such as the rheumatic diseases, which has been clearly established as the number one crippling disease in the country, being taught in less than one-third of the medical schools. Prior to 1950 there were, according to information that we have, less than three medical schools in the entire country teaching the subject.

The straight facts are that most physicians cannot economically afford to practice rheumatology which is a chronic disease, charge the prevailing schedule of rates to the patients that have the ability to pay, and still retain for himself a normal expected return on his investment of years of study. Therefore, the conclusion is that this is a disease that must be subvented through governmental agencies and through institutions.

- C. Our records indicate that the average patient comes to our clinic with the following history:
  - 1. They have had the disease for approximately 5 years before seeing any physician.
  - 2. From the time of their visit to their first physician they have seen in the next 5 to 7 years approximately 8 different doctors.
  - 3. Therefore, when the average patient arrives at the arthritis clinic, they have had the disease and time for it to develop and enroach with its damages upon the body for 12 to 15 years, and it is at that time difficult to do much other than to relieve the symptoms.

An important factor in this group of patients is that the greatest majority, in excess of 75 percent, of these patients

have been found to have been nondiagnosed, misdiagnosed or improperly treated, at least to the extent that the latest available forms of treatment were not prescribed for them.

A significant area of nonprescribed care has been in the area of physical unknown entity within the scope of the treatment of arthritis, a fact that should be considered as a priority item of the Arthritis Commission, i.e., the training of physiatrists, physical therapists, occupational therapists and trained nurse specialists.

A comprehensive program is needed--one of public education through community resources, using volunteer organizations to enlighten and educate the public to the dangers of this disease and the importance of early detection, proper diagnosis and treatment.

### III. MAJOR RECOMMENDATIONS OF THE FOUNDATION

- A. That the National Arthritis Foundation, on the supposition that they will be adequately funded for their program, make no blanket grants to medical institutions financially for the performance of general specified services, but rather that all grants, whether they be in each of the major four categories that the Arthritis Act is concerned with--primarily, research, professional education, public education, and patient care--be administered on a purchase-for-services system on the basis of bid.

It is recommended that the foundation shall create a national research committee to coordinate all research and to advertise for bids on research projects to individual medical centers, be they public or private, and accepted on the merits of the proposals submitted.

- B. For patient care--that there be established at least 15 arthritis diagnostic centers throughout the country, independent of, but most probably connected with, a major medical institution.
- C. That the fees for admittance to this clinic shall be based on the patient's family earnings and ability to pay.
- D. That they be coordinated and that diagnostic procedures be simplified and established in such manner that each of these centers provide a laboratory for diagnostic purposes available to all physicians in the state, primarily family practitioners to whom ultimately we shall have to turn for our initial contact with the arthritic.
- E. Our clinical experience has demonstrated that individual testing and lab procedures can amount to as high as \$15. Two specific lab procedures, such as gold serum level and E.N.A., are available in only a few major medical and private labs in the country. Each state should have complete facilities to provide



blood profiles at a cost of approximately \$20 to \$24, as opposed to the individual costs as previously mentioned.

- F. It is our experience and thought that basic research need not be confined specifically to departments of immunology and rheumatology, rather, opened up to senior research investigators within the scope of the general research community, medical institution, or private researchers and laboratories.

It is the general consensus of a major section of our Medical Advisory Committee, but not totally conclusive, that the major trust in early detection and diagnosis must be in the hands of adequately trained family practitioners. The rheumatologists role should be confined to a teaching and consultative position where their highly specialized training would be required.

It must be noted that this testimony as submitted is a personal review taken from the minutes and records of the foundation on a cumulative basis through the years. They do not necessarily reflect my personal opinions, nor have they been reviewed or approved by the individual members of the chapter's present Medical Advisory Committee, who may or may not agree with particular points at issue that have been raised in the testimony submitted.

ENGLEMAN: Thank you, Dr. Waller. I think we'll proceed to call on Dr. Hahn.

TESTIMONY OF  
BEVRA H. HAHN, M.D.  
CODIRECTOR, ARTHRITIS CLINICS  
WASHINGTON UNIVERSITY MEDICAL CENTER

HAHN: The subject I wish to address is education in the rheumatic diseases. Such education must be directed to the three "P's"--physicians, paramedical personnel, and patients. For all of these groups, current educational efforts are sadly deficient.

In regard to the education of physicians in patient care and research in the rheumatic diseases, the needs are great. Approximately 20 percent of the medical schools in the United States do not have an active, comprehensive teaching program in rheumatology. My experience indicates that there is great interest in this specialty among medical students; the problem, therefore, is lack of faculty qualified to teach in this area. In spite of the obvious need for academic rheumatologists, financial support for the education of such individuals is shrinking.

Allow me to illustrate the problem by detailing our experience at Washington University. Physicians who enter the practice of rheumatology, or who become full-time academic rheumatologists, receive their training in fellowship programs following house staff training. Currently, for the academic year (AY) 1975-1976 we have four fellows in rheumatology at Washington University. Each year 2 positions are filled; for this AY

there were 11 well-qualified applicants for those 2 positions. In AY 1976-1977, we will lose one salary provided previously by the Eastern Missouri Chapter of the Arthritis Foundation through a bequest. Therefore, in AY 1976-1977, we will train 3 fellows; there are already 14 applicants for the 1 position which will be available then. In AY 1977-1978, one more salary will be lost as the National Institute of Health Training Grant expires, and we will be training only two physicians. Those two salaries will be provided through clinical funds: no funds will be available to train individuals for basic research in the rheumatic diseases.

Thus, in the midst of a knowledge explosion in rheumatology, we have an ever-decreasing ability to finance the training of physicians to deliver care, to teach and to pursue basic research in these diseases. The ultimate results of this shrinkage will be even fewer educators. Even now, at Washington University we are able to accomodate only one-half of the medical house officers and medical students who request elective training in rheumatology because we do not have enough faculty. (Electives in rheumatology were requested by 100 percent of senior medical residents and 50 percent of junior medical residents in AY 1975-1976.)

If the primary responsibility of academic rheumatologists, the training of physicians in the rheumatic diseases, is increasingly inadequate, then the education of paramedical personnel and of patients will be even less adequate. The multidisciplinary team approach to patient care must be taught to all three groups. This requires combined efforts of rheumatologists, orthopedists, radiologists, physiatrists, physical therapists, occupational therapists, and social workers. Such a team approach, available only at highly developed medical centers, is of great educational value to all participants as well as an excellent mechanism to provide patient care. Formal teaching sessions in which rheumatologists, orthopedists, and personnel trained in rehabilitative and physical medicine share their information and talents should also be a part of every medical school curriculum.

For patients themselves, we need not only ready access to a multidisciplinary rheumatic disease program but also access to accurate, up-to-date, and authoritative literature concerning degenerative joint disease, gout, rheumatoid arthritis, systemic lupus erythematosus, ankylosing spondylitis, scleroderma, polymyositis, and drugs approved for the use in the rheumatic diseases.

Considering these great needs that exist for education in the rheumatic diseases, education which will result in research advances and improvement of patient care, I would make the following recommendations for utilization of Federal funds:

- (1) Establishment of funds for training fellows in the rheumatic diseases. The need for research fellowship grants is particularly great. NIH training grant programs could be reinstituted, or a new and similar program could be instituted under the direction of the Chief of the Arthritis Section of the NIAMDD. Stipends of approximately \$12,000 plus funds for supplies and travel should be provided. The current practice of



obtaining NIH training grants on the merits of a detailed research plan are beyond the capabilities of most physicians at the completion of their house staff training. Those physicians must have a chance to receive research training and a stimulus to enter academic medicine.

- (2) Establishment of rheumatic disease center. To provide education for physicians, paramedical personnel and patients, as well as to provide quality medical care, multidisciplinary rheumatic disease centers should be established in as many existing medical centers as possible. A major requirement for such a center must be the presence of a director who is well trained in rheumatology, physical medicine or orthopedics; a stipend for such an individual should be provided. In addition, the proposal should include a major emphasis on education at all levels including patients, students of medicine and of physical and occupational therapy, house officers, and fellows. The awarding of such grants should be the province of a special committee created for that purpose and reporting to either the Arthritis Director of NIAMDD or directly to the Secretary of Health, Education and Welfare. The establishment of such centers should provide medical schools with a mechanism and motivation to provide teaching and care in the rheumatic diseases.
- (3) Establishment of an arthritis information center (AIC). To provide ready access to current information regarding the rheumatic diseases, a committee of experts should be established to write authoritative booklets concerning arthritis in general, each of the most common forms of arthritis, and drugs and physical therapy techniques used in treatment. This literature should be revised at 2-year intervals. It would be available on request to patients or to physicians who wish to provide that material to their patients. Members of the AIC could rotate the responsibility for offering information directly to physicians via a hot line, which would permit the caller to contact an expert for direct information. The AIC would thus function to educate both patients and physicians.

ENGLEMAN: Are there any questions from the members of the Commission?

VOICE: I just wanted to ask Dr. Hahn whether she envisions this arthritis information center being established?

HAHN: I think this could be done as a separate institution. It would probably have to be shared by persons from all around the country and some kind of a central hot line established. Or it could possibly be established through the Arthritis Foundation by a committee appointed by them to design a mechanism that is more workable.

VOICE: Have you had experience with the hot lines?

HAHN: No, I have not. I understand that they are available in some of the V.A. systems. Is that not correct?



VOICE: Yes and also the National Library of Medicine has worked with some of them.

ENGLEMAN: Any other questions?

VOICE II: Assuming that you could get your 5 rheumatologists for your center, have you had some cost estimates for them?

HERD: No cost estimates in a formal sense. The round figure off the top of my head is on the order of \$250,000 per year to operate such a center.

VOICE II: That would be primarily for what?

HERD: Salaries.

MELICH: I'd like to talk to Dr. Hahn about her idea of communications with people through hot lines. I happen to know that in some areas they are very successful on a small scale, and since I have this idea in my report that's coming through the Education Committee, I am also impressed that you also feel that it is a good idea. However, on your information centers, how would you feel about having information centers within the structure of a center that is set up by the Arthritis Commission? I feel that a local input is just as important as something on a national basis and I feel that it would do more good. Do you agree with me?

HAHN: Yes, I do think there is an excellent idea. I think there could be a need for both. There are some situations in which we all find ourselves where a patient has a disease for which there are only a few people in the country working on whatever the particular complication is or special disease, and you learn so much in 3 minutes from picking up the phone and calling 1 of these 2 or 3 experts. We might not be able to provide total expertise at the local level. I think that we can probably provide, satisfy the needs of maybe 90 percent of community physicians through a local information center. I think that for the other 10 percent it might be useful to have a medical mechanism for getting in touch with one of the experts who are available in the country.

MELICH: I see it as two things. I think you have a patient that needs help immediately and then you also have the expert who also needs help. Maybe we are talking about the same things but in two different versions, and I certainly think that is a fine idea.

VOICE: I'd like to ask both Dr. Hahn and Dr. Zuckner to give us some estimate of what they feel would be the financial part required to support the programs that they have referred to.

ZUCKNER: I am not sure which program you are referring to specifically.

VOICE: We are talking about your training grants and that sort of thing.

ZUCKNER: I'd like to reiterate what I said before, perhaps emphasizing the other aspect, and that is that monies that have been given toward training have been used very fruitfully at this time and have been distributed in a way that is most efficacious for the general picture of arthritis. However, I do think that there has been some neglect in terms of some of the institutions; perhaps, this might include areas like Nebraska and some of the smaller schools.

It is very very difficult to get financial support. With the money that St. Louis University has gotten from the local chapter of the Arthritis Foundation, we have developed our section of arthritis at St. Louis University to a point where we have a full-time rheumatologist trained in basic investigation coming in next year, two fellows this year, a potential for three next year. Other personnel include a biochemist and an immunologist on a Ph.D. level, and this is small compared to what the major institutions have, but this is a tremendous amount compared to what we would have had if the foundation locally did not give support. Monies that should come in would be adequate for perhaps two staff members, one on full-time faculty and one on a fellowship program, and this, I am sure, would amount to a good \$30 or \$40,000 or so a year, for some of these institutions.

HAHN: Let me just give some rough estimates which I am sure some of the members of the Commission are more familiar with than I am. I think, to train a fellow, a research fellow for one year, to supply him with adequate research support and technician salary would run somewhere between \$30 and \$40,000 per annum to train each individual. For the arthritis center, if you are paying a stipend for the director, this is somewhere in the \$30,000 dollar range, and part stipends for other trained people who are participating in secretarial work and such, I think that would probably run around \$100,000 a year for that center, and if you wish to support any kind of extensive clinical research program, we think that would cost about an approximate \$25,000. Somewhere between \$100 and \$125,000 dollars per year would be an estimate I'd give for support of an arthritis center, and I think that's conservative. Too conservative, several of you are more qualified to do that than I am.

JENERICK: I was raising a question which I feel has no answer, but which I feel has to be raised, and that is with the growth and development of arthritis centers through the Arthritis Act in one city or another, we come to where will we find the manpower to create the registers and research assistants, etc? We just heard a case here where one state center has to rob another state with rheumatologists in short supply; it takes 15 years to make one. Is there any way through this madness?

ZUCKNER: Well, the most obvious answer that you have is twofold. I would say that a good percentage of the rheumatologists, certified rheumatologists that are now out in private practice, should be encouraged to leave private practice and we should pay them adequately to head up these institutions as teachers. But the courses should be taught to the general practitioner, family practitioner. You might ask--this is part of my original proposal--how can you force a University of Nebraska or N.U. or someplace to put this into their curriculum for the family practitioner, in a 5 or 6 year course? They have to know at least something about the

diagnostic procedures. Each university has its own system and may decide not to do it. Let me point out one thing. A number of years ago, I, under the guidance of one of our presidents who is long gone now, President Eisenhower, called together a meeting of men and women from around the country on physical fitness. Do you remember Eisenhower's program of physical fitness? As a result of his program, there are many states--and I have not taken a survey, but I know it applies to Kansas and to Missouri--you can be a straight A student in any high school in the State of Kansas, but if you flunk gym, you don't get a diploma and are not admitted to the any of the schools for whatever course. Now, if we don't have enough power and ingenuity when we accredit high schools around the country, to see to it that they incorporate the basic teachings in the fundamental programs of diagnostic work so that they can do it and leave the rheumatologists at the centers to do the teaching and the top diagnosis.

VOICE: Dr. Jenerick, you clearly must support training programs, because only from training programs can you breed the people you need to staff the additional centers. And this cannot be done overnight, it will take several years to feed people into the new centers.

HAHN: Now I want to get back to a point that I made which is that rheumatology is really a very exciting specialty and there is no lack of people lining up to train in rheumatology. If we could accomodate three-fourths of the people who came, we could train and flood the midwest with rheumatologists at both academic and practicing levels in just a period of a few years. There is lots of excitement about it. All you need is one interested person in a teaching area to communicate the excitement of this subspecialty. And I think that can be provided, if the training programs are created.

VOICE: You asked how we could solve the problem, to get out of this mess. I think it's very important to supply the money, that the money is there, for more people who will seek training or who will have the training made available to them. I don't think there is any question, as Dr. Hahn indicated, that the interest will be there, and you will get everything accomplished that you want in the field of arthritis.

ENGLEMAN: Thank you very much. I think we must now proceed to Dr. Kuhlman.



TESTIMONY OF  
ROBERT E. KUHLMAN, M.D.  
ASSISTANT PROFESSOR  
OF ORTHOPEDIC SURGERY  
WASHINGTON UNIVERSITY SCHOOL OF MEDICINE

KUHLMAN: I am an orthopedic surgeon and Assistant Professor of Orthopedic Surgery at Washington University School of Medicine engaged in the the private practice of orthopedic surgery in southern St. Louis. Although I have more than the ordinary background of basic science research, I am engaged in the application of clinical medicine to needy people. In particular, I see those who are injured either on the job, in automobile accidents or in the home and those who are disabled and afflicted by various forms of arthritis, and I feel that particular effort should be devoted to the management and care of these individuals.

Arthritis, in one form or another, is probably the most commonly occurring disease in the United States, at least as far as I can see. It afflicts young people and old people and certainly does disable them. We have made dramatic strides to improve efforts at rehabilitation with the use of total joint replacement and toward this end are accomplishing our goal.

However, I see neglect financially, socially and administratively, of some efforts being made to continue providing care to the arthritic patient in the urban areas. So much effort has gone to building brand new, beautiful hospitals in the counties and in the affluent surrounding areas but facilities such as the Lutheran Hospital, the Alexian Brothers Hospital and the old St. Anthony's Hospital have been pitifully neglected in making available funds to take care of the elderly people who remain in the city environment and who have, in fact, attempted to remain there because they cannot get out and obtain transportation in the suburban communities. This has become an increasing problem and some thought should be given to it. The remaining urban hospitals have been placed at a severe disadvantage in obtaining funding for improvement projects. They have been crippled by the inadequate compensation provided through the Medicare and Medicaid Act and the demand made upon them by patients with limited finances. In the last analysis it is always the hospital which is called upon to bridge the gap between what some government programs may provide and what meagre resources the individual may have.

Rehabilitation of the arthritic patient can save the government money by returning people to a useful existence, enabling them to earn their income and avoid welfare rolls and in many instances, returning them to work so that they can pay taxes.

And I have one last comment in regard to the current fashion of the screening and detection center as it may apply to arthritis, and to me this seems somewhat of a misapplication as there seems no need for screening and detection centers. Everyone who is walking about has arthritis in some degree or another, and it would be better in my judgment to have a reception center for these people with the purpose of education and guidance so they may be routed, where necessary, to appropriate

treatment in one system, and in the other, educated so that they may adapt to their disability in a useful and successful fashion.

ENGLEMAN: Thank you, Dr. Kuhlman. Who would man such a reception center, what is it called? Actually, who would serve at such a center?

KUHLMAN: Well, I think that the physician, unfortunately we always keep coming back to the physician, but I think it would be necessary to have a medical doctor who is trained in the disciplines and problems of arthritic patients, I think the social worker and I think that a nurse who has been attuned to the problems of the arthritic patient.

ENGLEMAN: Could such a reception center then be part of one of the many arthritis centers?

KUHLMAN: I think it would be best in the community hospital.

ENGLEMAN: Assuming the community hospitals have the manpower to handle this.

KUHLMAN: Yes sir. I think it would limit it to the larger community hospitals.

ENGLEMAN: Any other questions of Dr. Kuhlman? If not, we will continue and hear from Dee Aylward.

TESTIMONY OF  
DEE AYLWARD  
LICENSED PHYSICAL THERAPIST  
ST. LOUIS, MISSOURI

AYLWARD: My name is Dee Aylward. For the past 7 years, I have been employed as a licensed physical therapist, the first year in a pediatric hospital, the second in a general hospital, the last 5 in a home health agency.

In all of these facilities, my experience in treating people with arthritis has been extremely frustrating. Rarely have I been able to motivate patients to follow regularly the prescribed exercise programs. In addition, I've encountered severe muscle weakness in people whose joints are mechanically efficient and whose bedrest has not been excessive. Standard strengthening regimes must be geared to joint conditions which necessitate more frequent visits and a longer rehabilitation period. Many times weakness limits functional activity where pain and inflammation are not severe. Constant pain on motion naturally contributes to both of the above problems, but I don't feel it explains them entirely. More research is needed to study arthritis-related muscle pathology.

Over the years I've spent many agonizing hours worrying about how to make my approach to arthritis more effective. I've come to the conclusion that professional personnel alone can never provide the wide ranging support that is needed to increase the rate of compliance with treatment.

Depression appears to be a most significant aspect of the disease and should be recognized and treated early. Easy access to psychological counseling should be available. Exercise routines must be simplified and, if possible, incorporated into activities the patient performs daily either for work or leisure.

Home care is an excellent delivery method because of the ease of access for the patient. Home health agencies, however, are geared to acute care and they shy away from long term commitments. What is needed is a non-hospital based, local community program which could provide home therapy services, staff group exercise classes and O.T. activities, offer emotional support to members, sponsor services, disseminate information, and refer to and contact other community agencies for required facilities and services.

The thrust of the above suggestions is to shift responsibility for long term rehabilitation from the purely medical realm to the patients themselves with public and private support. Treatment of people with arthritis should emphasize close personal involvement with other people with the same tragically painful and debilitating disease.

ENGLEMAN: Thank you, Miss Aylward. Any questions?

BATCHELOR: I'd just like to respond to your proposals here by saying that one of the consultant groups working with the Commission is working along just the lines you outlined here to develop a more systematic approach to sources that are available or that could be made available in the community, shifting some of the responsibility from the traditional institutions base to the hospitals.

VOICE: I know that Dee Aylward has been involved in a patient group. I just wondered if you would like to make any brief comments on some of the benefits you have seen come out of that group.

AYLWARD: I can tell you more about the problems than the advantages. We have needed funds for mailing lists which were not available. Happily we were associated with the arthritis center at the university and were given our initial lists for contacts there and our stationary and stamps for our initial mailing. Since then the group has been able to raise their own money. There are problems as to whether they should remain an individual unit in the community, or whether they should become a part of the Arthritis Foundation. There is a lot of feeling that large organizations don't provide care down to the basic level--that the local group might be better. I'm not sure. I think there are a lot of problems with starting patient groups. There are group dynamics and personality conflicts. How do you motivate people to come? How do you reach them and how do you keep them once they are there? And it's very difficult--I found, in my experiences, because I haven't done this before--to really get a good group like this going. I think in Columbia there are a number of dedicated people who are willing and able to push it, but I think that a lot of times we need (inaudible) and we need a way of reaching other people in the community outside of the ones that are affiliated with arthritis centers, because most of the people who came to our group were



being treated by private physicians. They had very little knowledge of community resources that were available, like home health agencies, physical therapy treatment. The thing that has come out of this group is that there is a tremendous need to reach people with arthritis in the community, specifically Columbia. There are other places which have been active for a long time. When you are starting one up it is extremely difficult; and any assistance that you can get, financial and advisory, is very welcome.

ENGLEMAN: May we now hear from Jane Leopold.

TESTIMONY OF  
JANE LEOPOLD, M.D.  
DIRECTOR OF INFORMATION AND REFERRAL SERVICES  
UNITED WAY OF GREATER ST. LOUIS

LEOPOLD: One of the most difficult problems we face in trying to serve handicapped people is the provision of transportation to and from medical appointments, clinics, physical therapy treatments, etc. There are a number of agencies and groups who have transportation programs. However, each program has its limitations and restrictions such as; for certain diseases, special ages, for residents of specified geographic areas, or to specific clinics. Consequently, many have no available transportation. There is no general transportation service that will take handicapped persons who are confined to a wheelchair or stretcher to a medical treatment program. This is a crying need in our community.

Home nursing and physical therapy are available, but the cost of these services is high and in many instances out of reach of the people who are living on a fixed income. Despite the fact that these services are also available on a sliding fee scale and some covered under Medicare, there are still many victims who fall in between the cracks and are unable to receive these needed services.

Meals programs for the elderly are numerous in our community; however, a person must meet an age requirement, and there is emphasis on congregate meals. There are many persons who should be served in a home delivered meals program and cannot be served because of the limitation of transportation services to deliver the meal.

Homemaker services are almost nonexistent and companions are extremely difficult to find. It appears that it would be possible to find companions for the elderly and handicapped persons in their home if funds were available to pay a minimum wage to these persons. Screening and training programs would be an essential part of this.

Health and hospital equipment is available in some instances, but for the arthritis victim to obtain this service they must be served by the arthritis clinics and they must be indigent. We realize that these services are expensive and difficult to provide. However, with the proper planning and some financial resources, they could be provided to the arthritic victim in our community.

This is the testimony that I presented in writing, and having been sitting here listening to some of the people before me, it has come to my attention that financial assistance for medical care is one of the most frequent requests that we have in our information referral service. I do believe there is a great need to increase the ability of people to help to pay either through insurance or through Medicaid or Medicare programs, for the tremendous medical expense which we find when you have a crippling disease of this type.

ENGLEMAN: Any questions?

MELICH: I just have a comment. We were saying that, when we were in Milwaukee, there is a new kind of taxicab service for handicapped called Handi-cabs, and apparently it's doing very well, and it might be well to investigate Handi-cabs because they have all kinds of cabs available for all types of people. We have a Handi-cab service available to us through some of the mortuaries here, but it is very expensive. I also had a gentlemen call me about 2 weeks ago who brought a van by to demonstrate to me, which will provide transportation for 5 people in wheelchairs with a hydraulic lift and will take the wheelchair into the cab, and will also accommodate one stretcher. We are looking into the possibility of this now.

TESTIMONY OF  
DON W. ORSCHELN  
PRESIDENT, ORSCHELN LEVER SALES COMPANY

ORSHEIN: Fortunately, I am not afflicted with arthritis, nor to my knowledge is any member of my family. I have acquaintances who have arthritis, and I know from firsthand knowledge that many persons in central Missouri are afflicted with arthritis in one form or another. But, I have witnessed and participated in efforts to raise funds to support meaningful research in arthritis and realize how difficult it is.

Although the disease is very common, those afflicted usually do not have the funds available to support research in any meaningful degree, and few who have the money but not the disease can understand the need or be motivated to support such an effort. Many citizens simply believe that arthritis is a symptom of old age, and therefore they believe it is folly to support a program which can't be won.

It would not be my intention, therefore, to appeal to the Commission on the basis of my own personal medical need nor the medical needs of my family and friends but to testify as to the problems encountered in raising private funds in sufficient quantity to support the high cost of needed research and referral services which are necessary to seek the causes and possible cure of arthritis.

It is because of the extreme difficulty in securing the necessary funds privately, and because of the prevailing misconceptions of the disease, and it is because the disease is so widespread as to be considered epidemic, bringing with it untold pain and suffering, that I am in favor of governmental funding of the National Arthritis Act.

VOICE: unintelligible question.

VOICE II: I think what I have learned has come mostly from experience. When I first started working with the juvenile arthritics who were in the last stages of the disease, and severely debilitated, I went to the index trying to find anything I could to guide me in dealing with these children. There were no articles on management of psychological aspects of arthritis at all. I think you just do the best you can. I don't think anyone can solve the problem of compliance with treatment.

VOICE: I would definitely support a better training program. Of course, I haven't been connected with schools in a long time. I think they're doing an adequate job. They are doing the best they can with the amount of information that is available.

ENGLEMAN: Thank you very much. We will now complete the next group of witnesses.

TESTIMONY OF  
WILLIAM GAUNT, M.D.  
CLINICAL DIRECTOR  
UNIVERSITY OF MISSOURI-COLUMBIA ARTHRITIS CENTER

GAUNT: Experience since March, 1972, with a multidisciplinary arthritis unit at the University of Missouri Medical Center, Columbia, Missouri, strongly indicates the value of such a team approach in the care of patients with arthritis. There is a national need for the multidisciplinary care of patients with arthritis, and I urge that this need be considered in provision of funds for the National Arthritis Act.

The multidisciplinary arthritis unit at the University of Missouri-Columbia has been staffed by faculty from the Immunology and Rheumatology Division of the Department of Medicine, Physical Medicine and Rehabilitation, and Orthopedic Surgery with additional participation by psychiatry, radiology, pathology, and pediatrics. In addition, a diversified staff of allied health professionals including nurses, technicians, aides, ward clerks, physical therapists, occupational therapists, social workers, psychologists, vocational rehabilitation counselors, dieticians and health educators as well as medical students, interns, residents and immunology and rheumatology fellows have been directly involved with the unit.

Objectives of the multidisciplinary arthritis unit at the University of Missouri, Columbia are:

- (1) To provide an exemplary multidisciplinary diagnostic and treatment facility.
- (2) To educate patients, their families and team personnel in arthritic diseases.
- (3) To establish interrelationships with health care personnel of various communities.



- (4) To provide research programs aimed at determining the underlying causes of arthritis, developing new and more effective forms of therapy and implementing new knowledge as it is gained.

Advantages to patient care of such a unit include the rapid availability to the patient of the various team members and an adequate observation period of symptoms, signs and therapeutic response in a restful supportive environment.

Education of the patient occurs during rounds by the physicians and paramedical personnel, by provision of instructive booklets relating to arthritis and by instruction of the patients as they are seen in physical therapy, occupational therapy and other allied health services in the medical center. Education of the family is achieved by discussion of the patient's problems often with the family and patient present together. In addition, the entire family is encouraged to go to physical therapy, occupational therapy, and other services with the patient to learn how to help in the home care of the patient. Educational functions for the health team personnel include multiple rounds and conferences for the unit as well as discussions during consultative rounds on other services and in the arthritis outpatient clinics.

Interrelationships with health care personnel of various communities have included telephone discussions with the patient's primary physician both during the hospitalization and at the time of discharge, a discharge summary sent to the patient's primary physician, and also nursing, medical social workers, and vocational rehabilitation counselor determinations of availability of community resources. Furthermore, practicing physicians have joined the arthritis center team for some of its activities.

Clinical research on the unit is being provided by careful study of the patients who are admitted. As part of this, computerization of the data base of information in the near future should be helpful in the evaluation of patients with arthritis and should provide leads to optimum diagnosis and treatment.

Recently, a comparison of effectiveness of patient education on the multidisciplinary arthritis unit with that on the general wards was performed. The use of a questionnaire provided findings suggesting: 1) hospitalization of arthritis patients results in symptomatic improvement, 2) an organized education program is more effective in improving patient knowledge of arthritis than the approach generally used, and 3) better patient understanding of specific therapeutic agents can probably lead to their better use by patients.

ENGLEMAN: Thank you, Dr. Gaunt. Dr. Wells.

TESTIMONY OF  
JOHN H. WELLS, M.D.  
CHIEF OF STAFF  
MARTIN LUTHER KING HOSPITAL

WELLS: I am John H. Wells, M.D., Chief of Staff of Martin Luther King Hospital of Kansas City, Mo. I am a trained rheumatologist, who trained under the founder of middle west rheumatology, Dr. C. Stewart Gillmor. I am sure Dr. Gillmor selected me because arthritis was not a popular specialty, and, after all, he had to have someone to fill his quota for the arthritis program. As the first black doctor at General Hospital No. 1 in those days, I was happy to follow a man who had so much interest in the chronically ill. Ultimately, Dr. Gillmor felt that we needed a clinic in the community available to arthritics who could not help themselves or could not pay for treatment, and because he felt that General Hospital was getting too political.

I am here to speak with you on the several different categories of this act, namely research, patient education, patient care, professional training for doctors and allied health personnel, and the sociological implications and data bank. By sociological implications, we mean care and education for the public. And by public, we mean those who can afford to pay for health care, and those who cannot afford to pay for health care.

In my humble opinion, health care delivery under our present system is practically nonexistent for our low income, underprivileged inner-city residents. Suggestively, a center concept with probably a community center, where sick people could be referred or could come in to in the early stages of arthritis would be one of the answers. I assure you that minority people, farmers, rural personnel, Mexicans, blacks and poor whites, do not feel comfortable in some of these ivory-towered surroundings.

Some of these high-powered arthritic doctors do not feel these chronically ill people are sick, because, outwardly they represent such poor protoplasm. We must make our health care delivery system available to all chronically ill people, not only as a fact, but a must.

We must improve our health care delivery system to enable crippled, chronically ill people to be transported to the nearest available center, hospital, or medical school, regardless of boundaries, state lines or attitudes. Our Arthritis Center Board in Kansas City several years ago initiated a study to evaluate our usefulness to the community, affiliation with Medical Center, and need to the community. We felt needed and that we would try to hold on for the next 3 to 5 years until something like the National Health Act, in some form, would hopefully sustain our type of care to the chronically ill.

ENGLEMAN: Thank you, Dr. Wells. We will now hear from Dr. Zeiders.

TESTIMONY OF  
ROBERT S. ZEIDERS, M.D.  
CENTRAL ILLINOIS CHAPTER  
ARTHRITIS FOUNDATION

ZEIDERS: I represent the Central Illinois Chapter of the Arthritis Foundation which serves 82 counties in downstate Illinois. The magnitude of rheumatic disease there is reflected in the fact that more than 50,000 of the 3 million people in the region have contacted our chapter for information or for referral to specialists. Such care is provided by two rheumatologists at Southern Illinois University of Springfield, a private rheumatologist in Urbana, a handful of internists in our larger communities, physiatrists in Peoria, Springfield and Urbana, a few orthopedic surgeons whose interests go beyond the limits of reconstructive surgery and the monthly clinics sponsored by the Division of Services for Crippled Children.

The most urgent need in our area is the continuing medical education or postgraduate training of the all-too-few physicians and therapists already practicing in this large area. We share the Commission's concern with the obvious need for specialized training of both research-oriented and practicing rheumatologists as well as medical students. But their training takes time and our arthritics cannot afford to wait for the luxury of subspecialty care while their joints crumble. Such educational efforts are not likely to fulfill the needs of our arthritics if the current trends of geographic maldistribution of specialists are not reversed. The immediate answer to our patients' health needs must come from the physicians and therapists already available in their communities.

How can the National Arthritis Act best help the people of downstate Illinois? We would propose the establishment of a regional center consisting of medical schools, rehabilitation centers and the Arthritis Foundation facilities already existing in our area. The Central Illinois Chapter is the only organization in the region that presently unites all those currently providing specialized care to those who potentially need it. The medical schools and rehabilitation centers are best capable of conducting research and training programs whereas the Arthritis Foundation already offers public information programs and continuing education for health care providers. A specific suggestion for our 82-county area would be a mobile unit operated by the Central Illinois Chapter and staffed by paraprofessional personnel and regional specialists. Such a unit would make statewide visits, coordinated with the county medical societies who continually seek educational programs. Screening and detection could be performed by paraprofessional personnel who would precede the visits by the specialists. Those patients found to have significant rheumatic disease could be referred to physicians within the community with the aid of the medical society, or they could be efficiently referred to the medical schools, rehabilitation centers or existing regional consultants. The team approach to the care of rheumatic disease patients could be dramatically demonstrated to the local medical society, teaching these practitioners how to most effectively utilize their local and regional facilities. Such a mobile unit could then directly provide: 1) specialty care to patients and postgraduate training to physicians in medically isolated areas; 2) a referral source to regional medical schools with



their rheumatic disease units; 3) an investigative model for the delivery of specialty health care; and 4) a tangible service that might encourage sufficient voluntary contributions to the Arthritis Foundation to render the mobile unit financially self-sustaining, thereby reducing dependency upon Federal funding.

TESTIMONY OF  
C. ROSALES WYNNE-ROBERTS, M.D.  
RHEUMATOLOGIST  
SOUTHERN ILLINOIS SCHOOL OF MEDICINE

Wynne-Roberts: Ladies and gentlemen: I should like to draw your attention to small and/or new medical centers, such as the one at which my colleague Dr. R. B. Traycoff and I now work. We have just joined the faculty of S.I.U. School of Medicine located in Springfield, Illinois, in July of 1975 (this year) and represent the first two rheumatologists to come to the area.

I should state briefly that Dr. Traycoff was trained in rheumatology at the University of Pennsylvania and I was trained as a rheumatologist at the University of Michigan. We received excellent training at those medical centers and hope that we can use our skills effectively in Springfield.

Although we have been in Springfield only 4 months--a short period of time--we have been struck by the magnitude of the task before us of establishing a rheumatic disease unit in our area.

Firstly, there are few rheumatologists in the State of Illinois outside of Chicago. Dr. R. Zeiders is located in Urbana and Dr. Potter in Carbondale, no one in Peoria, and several in St. Louis, Missouri--a large center. Thus, to the best of my knowledge, there are a total of four trained rheumatologists to provide patient care, teaching or training and to undertake any research in southern Illinois.

Our main objective, or concern then is to set up an RDU which will provide the following:

- (1) Be a referral center for the diagnosis of those with rheumatic diseases, both adults and children (these latter especially, have been much neglected).
- (2) To initiate and provide additional diagnostic tests--and their quality control--in rheumatology, tests not currently available, needed to help evaluate patients.
- (3) To establish a center where at a modest cost patients can receive therapy such as gold; where patients can be assessed for aids, fitted for splints, taught home programs exercises (for which we need but do not have ancillary personnel), have access to an orthopedic opinion and, as necessary, surgery.

- (4) To take part in continuing medical education of colleagues, internists, family practitioners. (Our medical school has a large commitment to continuing medical education in the Springfield and surrounding communities.) To take part in training of residents in medicine and family practice in the better diagnosis and management of those with rheumatic diseases; to teach medical students the diagnosis and management of patients with rheumatic diseases. (Because S.I.U. School of Medicine is charged with training future physicians who are drawn primarily from, and many of whom will return to, the southern Illinois and adjacent areas, we, too, are a part of that charge.) To train future rheumatologists--within another 2 years, we would like to establish a fellowship in rheumatology, and offer training to future specialists. We would like to feel that we could offer all the accoutrements of a large center, including research experience.
- (5) Clinical research, including the establishment of a rheumatic disease data bank for our area which can be the basis of epidemiological studies, to study tissue and synovial fluid from those with rheumatic diseases.

These latter studies admittedly reflect our special areas of interest, mine as an electron microscopist specializing in ultrastructural morphology of connective tissue pathology; my colleague's as an immunologist-rheumatologist interested in some of the immunological responses in, for example, rheumatoid arthritis.

Needless to say, if we are to accomplish even a fraction of these stated objectives as component parts of a thriving worthwhile rheumatic disease unit, we need financial support, or more correctly and fairly stated, southern Illinois needs financial help to fight arthritis--a problem largely ignored in an area of approximately 3,375 square miles and a population of approximately 3/4 million. My point therefore, is to draw your attention to those trying to deal with arthritis outside the large centers and to suggest to you that some monies be assigned to such small areas up and down the country.

ENGLEMAN: Dr. Wynne-Roberts, as I understand it, you and your associate are the dubious core of a new group at your medical school.

WYNNE-ROBERTS: That's right.

ENGLEMAN: Let us say that under the Arthritis Act, \$100,000 was made available to you. How would you use the funds?

WYNNE-ROBERTS: Education is one of our biggest needs. I have been very impressed in just my few months experience at Springfield with how patients are receiving steroids unnecessarily because physicians are not aware of proper management of rheumatoid arthritis. I am aware that oftentimes a patient is given an incorrect diagnosis. And I suppose that about 50 percent of the time this is the case--not because our physicians are bad, but because they are undereducated when it comes to arthritis.

ENGLEMAN: How would you use the \$100,000 to improve education?

WYNNE-ROBERTS: Well, first of all we would get more people to help achieve this. We have an active program of lectures, for example. We've also established clinics because rheumatology is a very clinical subject, and people must learn by experience guided by those who do know the route of diseases and arthritis.

ENGLEMAN: Therefore would you seek out one or two physicians and would you form a salary stipend to attract professional personnel and others to the program? Is that correct?

WYNNE-ROBERTS: Yes, that's correct.

FELTS: I'd like to address I think a series of short questions to Dr. Gaunt because he touched on the subject that is of considerable concern to the Commission--namely arthritis centers. He described a functional unit that would meet the definition of at least one type of arthritis center, and I think there are a series of questions with which we are concerned, and perhaps his answers will bring us into a little better focus on that.

For one thing, Dr. Gaunt, I believe you stated that you had concluded that an adequate observation period in a controlled environment was very useful in the management of the patients with rheumatoid disease and arthritic conditions. One of my questions pertaining to this is that, in this day and age of cost control mechanisms, have you practically encountered problems with utilization review committees?

GAUNT: In our particular unit, the average length of stay was about 10 days, and seldom did it run over a month, and I don't think we have run into any major problems in that regard. There are, of course, patients using longer periods of stay, and we do have a rest rehabilitation center associated there as part of the medical center which will be providing longer term care for these patients. In answer to your specific question, our period of stay has averaged 10 days and has not been a major problem.

FELTS: Thank you. Another question along the same lines is what sort of patient volumes are you dealing with?

GAUNT: We have admitted approximately 600 patients since 1972, and we have a small unit right now of 8, I think its just recently gone to 9 beds, and we hope to expand this in the future. So this is primarily a small unit with time to bring in the total multidisciplinary team effort.

FELTS: What kind of continuing care do you provide after these patients are hospitalized?

GAUNT: We see them oftentimes again in the clinic, but primarily we are trying to make arrangements so that when they return to their small communities, and many of them are from small rural communities in Missouri, when they do return, that the physicians there are provided with the information to know what we found and have had a chance to discuss the problems with us, and we are hoping that much of the continuing care can



be carried on in the communities by the physicians and other allied health personnel in those communities.

FELTS: Have the professional interface problems been difficult?

GAUNT: No, I don't really think they have. I think there has been a good cooperativeness and, as a matter of fact, we have had physicians who had come up for periods of sabbatical, brief sabbatical periods of training and we put them on the arthritis unit, and we are hoping to encourage this further so that those physicians can provide a nucleus of care in small communities in the state.

FELTS: One last question from me. Is your unit self-sustaining economically or can it become self-sustaining?

GAUNT: It is self-sustaining at least in the same way that the rest of the hospital is.

LEWIS: I'd like to direct this question to Dr. Wells. First, I want to say that it is a pleasure, indeed, to see a black physician present. I am also of a minority sect. I have noticed that there are very few blacks in the field. Would you care to comment on why this is the case?

WELLS: This is very interesting, and you asked a very good question. In my opinion this is because rheumatology has been, with all respect due to the Commission, a white WASP ivory-towered type of conceptual mythological situation. Blacks are not invited into it; it is for the closed society. It is small, and until recent years, blacks simply did not have an entry into a situation where they could get a fellowship, or be trained by a trained rheumatologist who was in the interworkings or in the inner circle, as it were, and it has just been a difficult thing to break down. We blacks aren't invited into many other things until we get a Jackie Robinson type person to help break down the walls or until we get somebody like the late--I can't recall his name at the moment, who believes in trying to bring blacks into the mainstream, we're in for a hard time, and it has been a very, very hard time. This has been partly racial, partly attitudinal, partly localization, and partly financial and partly educational, primarily, because of the high level of attainment of rheumatologists--the long period of time necessary to study and the arduous, and the very little input financially into this same group once they have become rheumatologists. Thank You.

POLLEY: Mr. Wells, as one of the members of the panel, we are well aware that Dr. Stewart Gillmor--I must say that I think that he would be very proud of your accomplishments.

WELLS: May I reply to that? I thank you very much. You know Dr. Gillmor selected me, put up with me, and all these kinds of things, and then tried to drill it into me and we had some pretty rough days because Dr. Gillmor was a little older, as you know they called him "Stewing Stewart", and he would stew at me and half the time I thought it was because I was black, but I soon realized that wasn't the reason. He simply wanted to attempt to make me a capable rheumatologist, and I thank you very much for those remarks.

POLLEY: Well, they're sincere. I would like to address a remark to Dr. Gaunt. First of all, I think your testimony was very informative and it was the kind of information that the Commission needs. Secondly, do you have some data other than what you used in responding to Dr. Felts in regard to the evaluation of the program that might be made available as part of your written testimony?

GAUNT: Donna Holsten, our patient educator, I believe is going to make a statement later today. She is the primary person in this evaluation of the educational aspect, and I do have an abstract of what she is primarily involved in, and maybe she can say something further about that.

MELICH: Dr. Wells, I'd like to make you aware of some of the things going on in the Education Committee of which I am a member. And that is, we are recommending that we have what we call a patient advocate as part of the allied team. This is a person that recognizes the problems of cultural-ethnic groups and has been used in some areas very successfully, and we are also saying that this person will be the sympathizer, the buffer in other words, of all the problems that concern arthritics. I'm happy to say that the whole education committee has gone along with this idea, and you might find it interesting to hear our report.

ENGLEMAN: Dr. Wells, do I understand that the thrust of your recommendations as to how we may improve the delivery of arthritis patient care in the community, satisfy the needs of everybody you would place great stress on the center concept?

WELLS: That is correct--in some form. What I really mean is: How can we get help out into the community so that people who are trying to live, inflamed and deformed, can really feel good about going to a center or a school. It's a center concept in some form where they can feel good about going and believe that they can get some relief and feel good enough and well informed enough to go in in the early stages of their signs and symptoms, so that we can effect some type of help for these people. But the center concept, in some form, is what I do advocate.

ENGLEMAN: Thank you very much, and we will now call the next group of witnesses.

TESTIMONY OF  
ALINE R. PERKINS  
MOTHER OF PATIENT  
CHESTERFIELD, MISSOURI

PERKINS: I consider it both a privilege and a responsibility to make a statement to the National Arthritis Commission at this hearing as a concerned parent. Our youngest son, Bill, is almost 12 years old. Since the week of his 2nd birthday, when the diagnosis of JRA was made, our family has lived with the frustration, anxieties, and uncertainties of the future that are present when a child is a victim of JRA.

For 4 years Bill was treated with steroids in ever-increasing amounts. When we tried to ask questions about his condition, the side effects of the medicine, we were told very little. My husband and I became quite alarmed at the visible side effects of the steroids and were very distressed about his condition, and, through insistent prodding, finally obtained additional help. Fortunately, at this time, our son was referred to an excellent rheumatologist and, through his expertise, a thorough evaluation of Bill's condition was made and proper steps were taken to gradually reduce the steroids, substituting other medication. Why was so much time wasted in securing the advice and care of a rheumatologist? It is so important to secure all the help available as quickly as possible.

Our personal situation points up the need for public awareness. It is the children who may benefit from early detection and proper treatment. About 2 years ago a parents' group was started in the metropolitan St. Louis area. Those who have attended the three of four meetings held each year have found them to be informative, helpful in very practical ways, and have found a supportive group of people with similar problems and concerns. People have expressed repeatedly how much it has meant to be able to talk in a one-to-one situation with other parents. Somehow we need to reach more parents to help them become aware that such a group exists and that it can be helpful to the entire family of a newly diagnosed JRA child, or to the family and child who has faced the situation for many years. It helps to know we are not alone.

Another aspect gleaned from our situation is the need for continuing education of pediatricians and other doctors to help them become more aware of JRA. It is not a rare disease, seldom seen, when over 3,000 children are involved in eastern Missouri. How can it be detected and treated promptly and properly? I think there has been a vast improvement in this area during the past 10 years. It must continue.

Is HOPE only a pot of gold at the end of the rainbows, a fantasy, an impossible dream? Or is HOPE a viable word that can be vitalized and energized through research, a program which benefits future victims everywhere. We need financial support to contribute to the continuation of training of arthritis specialists at the three medical schools in western Missouri with progressive rheumatology programs.

In closing I would like to summarize my chief concerns:

EDUCATION of the public to the help that is available to JRA victims.



CONTINUING EDUCATION of the professionals and allied health professionals who must provide the care necessary to alleviate pain and to prevent, insofar as possible, crippling.

RESEARCH to find answers to our questions.

ENGLEMAN: Our next two witnesses are concerned with arthritis in children. So we will call on them before we call for questions.

TESTIMONY OF  
DENNIS M. O'CONNOR, M.D.  
CARDINAL GLENNON MEMORIAL HOSPITAL

O'CONNOR: The Cardinal Glennon Memorial Hospital has operated since August 7, 1969, a specific clinic diagnosing and treating children with juvenile rheumatoid arthritis, allied collagen vascular disease, and arthritis of other etiologies. The clinic currently has over 200 patients between the ages of 18 months and 18 years from the bi-state area.

Many of these children are followed routinely in clinics at Cardinal Glennon Hospital. There are a number of others that are referred for diagnosis and medical recommendations that are followed by their primary physicians in rural and urban areas.

The Arthritis Clinic is a multidisciplinary clinic headed by Dr. Jack Zuckner, rheumatologist, with rheumatology fellows, pediatricians, ophthalmologists and full-time allied health staff, such as social workers, physical therapists, occupational therapists and psychologists.

Funds from the National Arthritis Act would enhance this program both from the standpoint of health care, and to train more rheumatologists, family practice physicians, pediatricians and allied health people in the fields of arthritis, since early diagnosis and vigorous long term therapy is so very vital in this chronic disease.

The chronically ill arthritic child needs special help so that the total long range problems of the families, educational and psychological effect, as well as the emotional development of the child are kept in proper perspective to normal childhood for future goals of education, employment, and professional and social advancement.

Patients who are referred to the Arthritis Center at Cardinal Glennon Hospital are currently receiving these services. Cardinal Glennon has one of the largest pediatric outpatient departments in the United States, and if we are to continue to serve the tremendous number of patients now being seen, we will need additional funds to staff and train people who are vitally interested in working with not only the arthritic child but also with the chronically ill child and his family.

ENGLEMAN: Are there any questions the Commission would like to ask that are pertinent to Dr. O'Connor's testimony?

LAMONT-HAVERS: Did you tell us the number of patients with JRA that you have in your hospital?

O'CONNOR: There are 200 patients that have been registered through our clinic. Those are not all juvenile rheumatoid arthritis. We would also follow children with other types of arthritis, specifically septic arthritis, and also allied cardiovascular diseases, systemic lupus erythematosus, scleroderma--

LAMONT-HAVERS: Do you have any active patients now?

O'CONNOR: I am uncertain of the exact active number at this point. The 200 is the total registration in the 6 years of clinic operation. The active number is less than that, but it's still considerable.

LAMONT-HAVERS: Could I ask Mrs. Perkins, when did you become aware of the fact that you, as a family, were not unique, that there were others with children with JRA?

PERKINS: Only in the last 3 years.

ENGLEMAN: I wonder if either of you could tell us a little about the State Commission for Arthritis in Children?

O'CONNOR: The Commission is actually a group of concerned individuals that deal with the problem of arthritis in childhood and are looking into the problems that Mrs. Perkins has outlined with respect to better educational programs for both public and physician. I could not list the members. It consists of individuals both from the St. Louis area and from the University of Missouri and with representatives from the Missouri State Crippled Children's Service.

ENGLEMAN: Is this a self-appointed group or have you been appointed by the Governor?

O'CONNOR: I believe, but I'm not entirely sure, that we are a self-appointed group.

VOICE: I'd like to comment on that. This, I believe grew out of the Arthritis Conference called by a former governor of the State of Missouri several years ago. There were a number of work groups, committees, action committees that just grew out of that program.

POLLEY: Dr. O'Connor, I may have missed this point, too, but are you a pediatric rheumatologist, and if so, where did you get your training, what programs are available for the training of pediatric rheumatologists, and if you're not a pediatric rheumatologist, what percentage of your staff are rheumatologists?

O'CONNOR: I am a pediatrician, not specifically a pediatric rheumatologist. The number of pediatric rheumatologists per se in the country are very limited. There are some training programs now in existence that can further train people in the field of pediatric rheumatology. The percentage of our time spent in rheumatology is hard to

define. I am more a pediatric consultant to the clinic than the primary rheumatologist. The clinic meets one afternoon a week currently and then there are periodic consultations in the hospital for hospitalized patients associated with that.

POLLEY: Then Dr. Zuckner is the primary rheumatologist. Is that it?

O'CONNOR: He is, and his associate, Dr. (inaudible) and the fellows in rheumatology training under him also are associated with the clinic.

ENGLEMAN: Thank you. It is my understanding that Governor Bond who was to appear is unable to appear, but Dr. Sisk I believe you are going to read a statement of his.

SISK: I think the Commission probably already recognizes that there is a significant interest on the part of the people of Missouri to get us out of the doldrums in the fight against arthritis. I have a letter from Governor Bond, which I'll take this opportunity to read to the group, that attests to the interest on the part of the Governor.

TESTIMONY OF  
THE HONORABLE CHRISTOPHER S. BOND  
GOVERNOR OF THE STATE OF MISSOURI  
PRESENTED BY CHARLES SISK, M.D.  
ASSOCIATE PROFESSOR OF MEDICINE  
UNIVERSITY OF MISSOURI-COLUMBIA

SISK: "It is a pleasure to welcome the National Commission on Arthritis to Missouri.

"The Arthritis Foundation has estimated that there are approximately 450,000 men, women, and children in Missouri who have arthritis severe enough to require professional care. Missouri is fortunate to have at least three large university medical centers with nationally recognized education, research, and clinical programs in the rheumatic diseases. These centers offer a multidisciplinary approach for optimal care of the chronic arthritic patient, including internists, rheumatologists, orthopedic surgeons, physical therapists, and social workers.

"Our three fine centers, located in St. Louis, Columbia, and Kansas City, are not able to provide these services to all Missourians in need of such intensive care. This is the reason the Federal funds authorized under the National Arthritis Act should be appropriated by Congress, in order to establish a network of comprehensive centers across the state to inform or treat those citizens in the state who do not have easy access to the comprehensive treatment facilities already established.

"I encourage interested citizens to attend the hearings of the National Commission on Arthritis at St. Louis University to express their concern over full funding of the National Arthritis Act."

I'll add one point to that. There is consideration being given right now to the possibility of forming a Missouri commission on arthritis.



We're pursuing that point with the Governor, and providing him with additional information.

ENGLEMAN: Thank you, Governor Bond, and thank you, Dr. Sisk. I will now call on Margaret Carey.

TESTIMONY OF  
MISS MARGARET CAREY, SUPERVISOR  
SERVICES TO HANDICAPPED, OLDER, WORKERS, AND WOMEN  
MISSOURI DIVISION OF EMPLOYMENT SECURITY

CAREY: Thank you. I am Margaret Carey. I'm Supervisor of the Services to Handicapped, Older Workers, and Women, for the Missouri Division of Employment Security.

I have been employed with the Missouri Division of Employment Security since January 9, 1939. In 1958 I was made Specialist for Older Workers in St. Louis, a job newly created in the Employment Service Offices throughout the country, under the direction of the United States Department of Labor. In 1962 the job of Supervisor of Services to the Handicapped was added. Except for a few years some years ago, I have retained this second assignment. In both of my jobs my work has been that of a catalyst between my office and the community, including agencies, individuals, schools, and industry.

I am a member of the Governor's Committee on Employment of the Handicapped; a member of the Committee on Public Education and Community Relations for the Arthritis Foundation, the Eastern Chapter; the Federal Executive Board Committee on Employment of the Handicapped; the Governor's Advisory Council on Aging, of which I am Chairman of the Committee on Advocacy and Participation.

In my job, and in my outside activities, I am contacted very often by people who have arthritis, some in the beginning stages, some crippling to the extent that they feel a burden to humanity. In view of the great percentage of persons 60 years of age and over, as well as the children and young adults who are in this category, I have talked to everyone who would listen about the great need for research and therapy for these many people.

There is a young woman in my office who started to have arthritis when she was 19, and is now 23, becoming seriously burdened by this disease. I call it the disease that is not dramatic and a fast killer. We must emphasize that if this condition is not given the greatest possible nationwide consideration, particularly by all areas of government, we will soon find that its inevitability for most people, if they are employed or not, will add further to the cost of health care and inability to assure a pain-ridden future for those of our young who will have our country's future in their hands. May those hands be able to grasp not only mentally but physically the crucial needs of our country.

How can a person with no real hope that this painful and disabling illness will very likely not get progressively worse if a real solution is

not found have hope? We are confronted on all sides by national, state, and local problems. Many of our most brilliant citizens from all fields of work or study have suffered with this disease.

I address many groups of people, particularly handicapped and/or older, and the story is always the same. One of my favorite ways of starting to speak is to raise my hand and ask, "How many of us have some form of arthritis?" How often I have seen the flood of hands and thought, "Why must this be? Why is this a sort of a secret disability that many people feel shame for having?" Is it because when one tries to get onto a bus, one walks strangely? Is it because we who have felt its grasp on our body and on our minds know that in many cases present health care is, through no one's fault, merely a palliative, not a hope for a pain-free future? Is retirement, which should be a happy, perhaps carefree stage of our lives, a thing to dread, with our young dreams shattered, while we wear a forced smile on our faces so that our loved ones will not suffer vicariously?

What are the answers to my questions? There really are none, are there? Yet nothing can be accomplished in this world without the will to do and the means to do it. So many have the will: our physicians, our nurses, our therapists, our hospital aides, and so many, many more. I once heard a very wonderful physician say that if enough money were available, cancer could very well cease its killing of so many of our people. Yet the victim, and he is truly a victim, perhaps because of our shortsightedness, starts out on what will probably be a long road, not in itself leading to death, unless you can call the pain of arthritis something that could become a living death.

I would like to add one comment to my written statement. Many people, whether they are knowledgeable or not of what arthritis is, buy copper bracelets. Copper is an expensive metal. There is another metal which I think could do a terrifically more important job for the arthritic, which could come from industry, from foundations other than the Arthritis Foundation, which is already trying its best to get this, and from government, and that is gold. Thank you.

ENGLEMAN: What kind of gold?

CAREY: This kind.

ENGLEMAN: One of the famous forms of treatment of arthritis is gold salts.

CAREY: I'm thinking of the kind that buys things.

ENGLEMAN: Before we proceed with questions, I will come back to Dr. Sisk. I understand you had your own testimony to present. Would you like to give that at this time, Dr. Sisk?

TESTIMONY OF  
CHARLES SISK, M.D.  
ASSOCIATE PROFESSOR OF MEDICINE  
DEPARTMENT OF MEDICINE, DIVISION OF IMMUNOLOGY AND RHEUMATOLOGY  
UNIVERSITY OF MISSOURI-COLUMBIA SCHOOL OF MEDICINE

SISK: I must compliment the Commission for their endurance in this great campaign they're making across the country. I certainly empathize with your ability to listen to all of these things.

As most of you know, I was Medical Director of the National Arthritis Foundation for a few years, in 1973 and 1974. What I'm saying is perhaps a repetition of an old theme. Nonetheless, I want to reemphasize it because when I was in the foundation I was duly impressed by one thing: training in arthritis. I want to say that I think this is really where the action is. I want the Commission to recognize, too, if they don't already recognize, that we talk in grand terms in the National Arthritis Act about training, but there isn't really any designation within that act of training funds. I hope the Commission does come up with some clear, discrete statements in this regard.

As I said, the withdrawal of Federal funds for training in arthritis was particularly distressing to me while I was at the foundation. I think the quickest and surest way to stop the progress in the fight against arthritis is for the Federal Government training programs to stop for the arthritis specialists.

If one assumes that a physician's formal education in the treatment of a disease equates with his ability to deliver care to patients with that disease, the following statistics are pertinent, and I think most of you know this, but I'll repeat it at the risk of being repetitious. Forty of our 114 medical schools do not have a rheumatic disease unit. In other words, these are institutions which have one or less rheumatologist. In fact, 26 of our institutions do not have a single rheumatologist on their staff, and 14 only have 1 rheumatologist. Eighteen of our 23 newest medical schools have not been able to acquire a full-time faculty member in rheumatology.

Attesting to the inadequate training exposure of medical students and house officers, I think I will cite the following figures again from the manpower study, which is old, and with which I'm sure you are familiar, but it's worth repeating. On the average, for all medical schools in this country, medical students receive about 11 hours of preclinical training in the rheumatic diseases. They receive about 10 hours of mandatory training on the average. Less than 1,000, out of a total of 43,000, medical students in all 4 years of school take an elective in rheumatology. Only 15 medical schools have mandatory rotation for house officers in internal medicine, and the average of these rotations is 1.8 months. Less than 700 residents, out of a total of approximately 15,000 residents in medicine, orthopedic surgery, pediatrics, and physical medicine combined, took an elective in rheumatology in the year 1971-1972. The average duration of these rotations was 2.3 months. I think these figures leave little doubt that the majority of American physicians are untrained and thus unprepared to treat arthritic patients.



Let me also recount a bit of history. I'm sure the people in the government here know this well. In 1966, fellowship training programs in rheumatology were being supported by Federal monies in 41 institutions, representing a total of 94 trainees. Although these numbers seem small, it can be pointed out that 75 percent of all academic rheumatologists had either received or were receiving their training through these programs. This came about because, in contrast to other subspecialties, the majority of these individuals entered academic careers.

Despite the obvious benefits deriving from these training programs, since 1966 the numbers have dwindled until presently we have only 27 programs operational. As evidenced by the figures I have just cited, the above decline occurred in medical schools before they obtained that "critical mass" of rheumatologists to teach American physicians the minimum basic concepts in the care of arthritis. I think it can be paraphrased from a meeting of the American Association for the Advancement of Science in 1973. The deficiency in medical school training was reflected in the comments of a panel at this meeting when they said physicians "are trained very well to treat 15 percent of man's ills, but the other 85 percent, the simple primary health care needed by most persons, is neglected." I think arthritis certainly represents the epitome of this neglect.

Despite this painful deficiency of manpower, the Government proceeds in its merry way to continue to phase out rheumatology training. As a matter of fact, I think in Fiscal Year 1977, before the National Arthritis Act comes into being, there is a big hiatus in here. The question is, "Where do we get training money?" I think we should act on this very, very quickly. The whole concept of the Government's reaction to training in rheumatology has been one, in my opinion, of sheer madness.

I can cite a few other figures that are worthwhile, I believe. One of them is that over the next 5-year period, if phase-out of Federal training goes into effect, we're going to have about a 50 percent reduction in the total research effort in the rheumatic diseases.

Because rheumatology is unique in the sense that it has not allied itself with vital hospital patient care operations, the phase-out of Federal training funds will exert a much more profound effect on this subspecialty than the other subspecialties: cardiologists oversee the operation of intensive care units; hematologists supervise blood banks; and pathologists take care of the clinical laboratories. Such an arrangement permits the acquisition of large full-time staffs for these subspecialties salaried out of patient care funds.

Rheumatologists do not find themselves in this favored status. This is certainly reflected by the fact that, of the 27 training grants we reviewed while I was in the foundation, 86 salaries, 86 staff salaries of the academic staff (instructors, and assistant, associate and full professors), or approximately 30 percent of all rheumatologists, would be lost due to this phase-out. These losses do not include either the loss of salaries due to dwindling program project grants or special traineeships.

The arthritis centers in our medical schools and larger medical institutions are certainly the nucleus on which to strengthen our attack on arthritis. Through them virtually all other nonspecialist physicians obtain their only training in the care of the arthritic. Without them, the next several years will be characterized by a generation of physicians who are incapable of providing proper care to patients with rheumatic diseases and by a lack or stagnation of any progress in our pursuit of improved therapy or better treatment for this group of diseases.

The rheumatologist within the framework of the arthritis center must, himself, serve as the standard of excellence by which the nonspecialist and allied health professional can mold their own concepts in treatment and management. He must provide the leadership to conceptualize and explore new methods of maximizing quality care for the arthritic.

One last point: the allied health professional has been totally neglected even though we recognize that he is an individual who has a lot to offer. With the basic, minimum care of rest, proper exercise, and aspirin, we can do a lot for rheumatoid arthritis. We know that. Yet, we have not one training program in this country for the specially trained allied health professional in arthritis. That's a very disappointing and sobering fact to me.

I think, lastly, through research and our arthritis centers with these people certainly is the only way we can pave the way for therapeutic advances in our field.

Thank you.

ENGLEMAN: Thank you, Dr. Sisk. You say there's a great need for training. Training for what?

SISK: Training the specialists in rheumatology, and training the allied health professional.

ENGLEMAN: To do what?

SISK: Two avenues: The first avenue is patient care and teaching, combining them as one.

ENGLEMAN: This was not the concept of the training programs supported by the NIH.

SISK: I'm well aware of that.

ENGLEMAN: So your suggestion is that this should be changed?

SISK: I'm suggesting that it should be added onto it.

ENGLEMAN: Added on?

SISK: Yes.

ENGLEMAN: You would divide the training chores into research and taking care of patients?

SISK: Yes.

ENGLEMAN: Any questions? Do you have a question?

LEWIS: Yes, I have a question. At the present time, the Federal Government is not supposed to be in the business of providing money for professional training other than to those professionals who are going to, after their training, work in Government agencies or Government hospitals. Are you saying that perhaps we need to be dogmatic enough to say that the Federal Government perhaps needs to provide some funds for a crash training program in the field of rheumatology, say, for example, for 5 years; and after that 5 years is out, the Federal Government will not be in the business of providing money for training?

At the present time, the fellow is, indeed aware that the Federal Government is providing for training. It's more or less a coverup. But the concept of money keeps popping into the picture, and it will all be given back to the United States. Evidently, the Federal Government's going to have to go out on the limb, so to speak, and start providing more money to train people in the medical profession in rheumatology if we're going to get the job done.

I'm saying, if this were possible and the Federal Government would say, contrary to the national health policy, "Yes, we will fund so much money for 5 years to train a large number of rheumatologists," approximately how much training time would you say said rheumatologists would have to have in order to become certified as rheumatologists?

SISK: Those standards are already established. The American Board of Internal Medicine says that we have to have 2 years of specialty training and subspecialty training in rheumatology, and this is what I think we have to follow.

LEWIS: Let's assume that there is a type of patient who wanted, through continuing education, to get some funds so that he could qualify. Approximately how many clock-hours of training would you say he or she would need?

SISK: I can't make a projection on that. I do know, however, that they have to have some kind of formal exposure in an institution where there are rheumatologists who are training. Obviously, I don't think there will ever be enough rheumatologists around to take care of all the arthritic patients. But I think you have to say to yourself that every medical institution we have in this country that's in the business of training doctors should have some expertise around to teach these other doctors, to teach these nonspecialists. The amount of time it takes I think depends upon what these other persons are doing and what their job is.



LEWIS: I have another question. If more money were provided to help train more rheumatologists, do you feel that other areas of the medical field would also be given access to more money?

SISK: There are supporting things that we can document more rheumatologists for. For example, there are fewer academic rheumatologists than there are in other subspecialties in internal medicine, perhaps with the exception of allergy. So there is, indeed, a numbers need here. On an absolute basis, we do need more people. There's no question about that, especially when you consider the magnitude of the arthritis problem.

The Federal Government has trained to date 75 percent of all rheumatologists, approximately. Now they're cutting out this program. As it stands right now, if they stop dead, cold right now, there would be a 50 percent reduction, approximately. I don't think we have the wherewithal outside of the Federal Government to train the people we need. The Government's going to have to give them a boost over time.

LEWIS: That would have to be the training.

SISK: Yes.

VOICE: Dr. Sisk, you touched upon a very key issue relating to the generation of monies by teaching institutions who support rheumatology. I think that what you have suggested is that teaching programs within the medical schools perhaps are being constructed where the clinical money is. Do you, indeed, mean this?

SISK: Yes, I definitely mean that.

VOICE: And not necessarily where the patient need or disease statistics may occur?

SISK: I also mean that, yes.

VOICE: Summarizing, then, you really are directing attention to what you perceive to be a need for a reallocation of dollar resources in medical school curriculum?

SISK: Yes.

VOICE: As you can see it, with your broad exposure, background, and all the time that you've devoted to this, generating these funds through patient care, no matter how exemplary your center might prove to be, is this probably an unreal goal?

SISK: I think it is definitely unreal, yes.

VOICE: Thank you.

ENGLEMAN: Thank you very much. We will now hear from Gini Laurie.

TESTIMONY OF  
GINI LAURIE  
EDITOR AND PUBLISHER  
REHABILITATION GAZETTE

LAURIE: I'm Gini Laurie. I'm a volunteer and editor of the Rehabilitation Gazette, an international journal and an information service for the disabled.

The stupendous conquering of poliomyelitis through well-funded research is proof of the value of research as an investment. It would be impossible to calculate the savings since polio was arrested in 1955, just 20 years ago. Consider the numbers who are alive and untouched by polio; the millions of dollars in earnings that were not lost because of death or disability; the millions of dollars in medical care (hospitalization, equipment, personnel) that would have been involved if polio had continued its rampage throughout the world. When research conquers arthritis, as it conquered polio, even more savings will be realized because arthritis involves many more individuals than polio or any other disability.

Polio research was supported by Federal grants as well as by massive infusions of money from the American people who were touched emotionally and who poured out millions of dollars through the March of Dimes. Money for research is the only way to conquer arthritis. Since arthritis is not primarily a child's disease, it cannot use the money-raising appeal of a winsome poliomyelitic child in braces on the lap of the President of the United States. Consequently, the support for research on arthritis must come dispassionately from all people through the support of the Federal Government. Thank you.

ENGLEMAN: Thank you, Ms. Laurie. Bertha McAlpin?

TESTIMONY OF  
BERTHA MCALPIN, R.N.  
PATIENT, ST. ANN, MISSOURI

MCALPIN: I am Bertha McAlpin. I am an arthritis patient. Because of this, I have experienced problems in housing, travel, recreation, housekeeping, transportation, family and social relationships, and medical care.

The Arthritis Act needs funds for research, education, public information, and patient care and treatment (rehabilitation, joint protection program, physical and occupational therapy, housekeeping and transportation, recreation, and social service counseling). Other Federal programs should adjust their requirements considering arthritis as a long term illness so that all arthritis would benefit. The unemployed could aid the arthritis patient. Thank you very much.

ENGLEMAN: Thank you. Father Cervantes?

TESTIMONY OF  
REVEREND RONALD H. LIND  
DEPUTY COMMISSIONER FOR SENIOR CITIZENS  
THE MAYOR'S OFFICE FOR SENIOR CITIZENS

LIND: Sir, I'm not Father Cervantes. I'm the Reverend Ronald H. Lind, Father Cervantes' Deputy Commissioner for Senior Citizens. Father Cervantes could not be here today, and I speak in his stead.

I'm representing today the Mayor's Office for Senior Citizens of the City of St. Louis. Our concern is for the welfare and the problems of all elderly people on the territory of the City of St. Louis, numbering somewhere in the neighborhood of 100,000 persons. For us, also, we are concerned with persons that we can identify as handicapped, and we tend to think of handicapped people as persons who are old before their time. Our aim is to broaden the lives of these people, to offer them options. We deal with them at a very, very nitty gritty level, and we deal with the results of years and years of problems that they've had in the past. The chief characteristic of aging, of course, is that limitations come upon us. And, believe me, when we see the limitations that are brought to the people as a result of arthritis, we know that we have some tremendous problems.

Our function is to provide money for certain services through Titles III and VII of the Older Americans' Act of 1965, and now Title VI, and still to be Title XX of the Social Security Act. The big push right now, of course, is in the area of Title XX. Specifically, the services that we offer to the elderly are, among others: information and referral, chore services, transportation, and such things as home delivered meals. It is in those particular areas that we deal with arthritic elderly people probably the most. We try to provide some kind of service in their home that will make up for the fact that they can no longer do the chores around the house. We break our necks and our brains trying to figure out better systems of transportation in order to move some of these people around and get them to the doctors, and such, and also consider all the things that need to be done about improving the technology of buses, for example, to make it possible for elderly people and arthritic people to get on more easily.

The real point of what I want to say is this: we pick up the pieces of broken lives. We pick up the pieces of lives broken by many of the infirmities of age, including arthritis. To pick up the pieces of broken lives after they have been so broken for one reason or another is expensive. We are about the business of spending Federal monies at the other end of the line, not near the beginning where the possibility of some sort of improvement in the person's physical condition is really there. We are dealing with people who, if they are arthritics, have had arthritis for years. I would have the group here check into some of the costs that are looked forward to, for example, through Title XX of the Social Security Act. This is to provide social services needed by people who need such social services for a variety of reasons, including arthritis.



I, for one, and I think I represent the opinion of Father Cervantes and the other people here, believe that it's much better to do a better job of prevention of the difficulties that come upon us most strongly with age. Therefore, we strongly urge the investment of any kind of money, in any direction, that will improve research and go to the extent of moving to eliminate the scourge of arthritis from mankind.

ENGLEMAN: Thank you, Reverend Lind. Dr. Whitson?

TESTIMONY OF  
S. WILLIAM WHITSON, Ph.D.  
ASSOCIATE PROFESSOR, DEPARTMENT OF ANATOMY  
SOUTHERN ILLINOIS UNIVERSITY SCHOOL OF DENTAL MEDICINE

WHITSON: Thank you very much. My name is Dr. William Whitson. I hold a Ph.D. in anatomy. I'm an associate professor at the Southern Illinois University School of Dental Medicine, in Alton, Illinois, which is a neighboring Illinois suburb of metropolitan St. Louis.

Although I do not wish to minimize in any way the vital importance of preprofessional and public education, the postgraduate training of rheumatology specialists, and the improvement of diagnosis and treatment of the rheumatic diseases among general practitioners through advanced education, I believe that the real hope in the fight against the diverse group of rheumatic and multisystem connective tissue diseases remains in adequately funded research.

I feel strongly about greater funding in the rheumatic diseases for research for the following reasons:

First, I have been involved in research on the ultrastructure of bone and cartilage treated with steroids since commencing my predoctoral graduate studies in 1966. I am currently developing electron microscopic histochemical techniques for the study of cartilage and bone with possible application to the synovium.

Second, I received all of my training through a combination of support from an NIH training grant and both predoctoral and postdoctoral NIH fellowships. In addition, my major professor at Arkansas, Dr. Howard Suzuki, was being supported by the National Institute of Arthritis, Metabolism and Digestive Diseases for the duration of my predoctoral training. For these generous opportunities of training, I feel an obligation to contribute to this research area.

Third, I have actively sought NIH grant support in the past, only to have my grant approved but not funded.

Of course, I am not alone in not receiving funding. It should be of concern to this Commission that money for research for the National Institute of Arthritis, Metabolism and Digestive Diseases has not kept pace with the other institutes. Literally hundreds of qualified investigators, whom NIH has paid millions for their training, are not able to receive funds to pursue their research ideas. This is particularly

true of the younger investigators. I fail to see the logic of training an individual to do research, having that individual generate a project judged to be of merit by his peers, and then not funding the project.

Scientists like myself know we can contribute, but we are rapidly becoming frustrated at continual rejection. The rate of funding for veteran investigators is too low, but the younger investigators are the ones who are feeling the brunt of this lack of funding. Ladies and gentlemen, the maximum progress in research against arthritis cannot be realized if fresh ideas and new approaches go untried and untested. Protect your investment in our education by giving us an opportunity to contribute.

Even the projected \$50 million over 3 years is not adequate, considering all the areas other than research which need attention. I, therefore, should like to suggest an alternative aimed at the young investigator, which I trust warrants your consideration as a recommendation.

In order to stretch the projected funds available for research, a program similar to the one which has been successfully initiated at NIDR in recent years should be adopted. This relatively low cost program is awarded for a maximum of 3 years, and is designed to fund young investigators who have not as yet received funding elsewhere. These limited grants insure the young investigator's continued interest and activity in research. The grant proposals go through the identical peer review process, but once judged meritorious, they are placed in a separate competition for funding. What I am asking is that you please provide us with the opportunity to prove our worth in this research area. If we do not measure up, do not fund us further.

In summation, we have been searching for the answers to the puzzles of arthritis with limited success for a long while. Increase the funding of our senior investigators, yes, but do not forget the future senior investigators. I, as one of those future senior investigators, actively solicit your help in giving me the opportunity to become just that.

ENGLEMAN: Thank you, Dr. Whitson.

BATCHELER: I would like to respond to this discussion of the competing interests in terms of training and clinical training, and make reference to the fact that one of my continuing responsibilities to the institute is in the area that is now under discussion. I would offer one observation that may help to give a fix on the dilemma that our Chairman has proposed here.

We at least have a start on the research training side in that we have authority and we also have funds that enable us to continue on the research side. But as my partner on my right, Dr. Lewis, has indicated to you, the urgent consideration is: What should the Federal Government do in the area of specialty training? This is, indeed, a very complex issue. It is important for you to realize that there are individuals and groups within the Federal Government that have been addressing themselves to this issue, and, clearly, are struggling with such questions as this: given a

finite pool of trained individuals with professional degrees, how can you rationalize the distribution of specialists within this very limited pool? I raise the question not because in a second we can hope to discuss all these issues in any detail, but it's important, having raised them, to realize that we have to confront them.

ENGLEMAN: Thank you very much. Celeste Hesser?

TESTIMONY OF  
CELESTE HESSER  
PATIENT, ST. CHARLES, MISSOURI

HESSER: I am Celeste Hesser. I am a rheumatoid arthritic patient. I'm a patient of Dr. Zuckner and Dr. Auclair, although that's incidental. Those are my doctors.

"Take care of yourself" is a casual remark people often say to each other. I have spent 4 years as a victim of rheumatoid arthritis, and "taking care of myself" has been my principal activity. If I relax just a little from a strict routine of medical and physical therapy, I am flattened by this viciously painful disease and need extra care by my rheumatologists. I must work very hard to regain lost progress. No matter how careful I am, there are still flareups.

It is my sincere hope that P. L. 93-640, the National Arthritis Act, will be fully funded. I am one of millions of Americans and people all over world who dream of being cured. May the research funded by the Act produce the miracle.

This disease has taken me from an active life of community service and a career in teaching to that twilight world of the semi-invalid. I am very fortunate to be under the care of skilled rheumatologists. I am also fortunate to live near their office. Many patients must travel over 100 miles each way to come for their appointments. I hope the National Arthritis Act will make it possible for more rheumatologists to be trained so that many more arthritics can have the level of good care that helps me.

I am constantly amazed by the simple ignorance of the general public regarding this disease that strikes 97 percent of all individuals over age 60 to the level to be seen in X-ray films. The National Arthritis Act could do much in the area of public education so that victims of this disease could have early diagnosis and treatment. Many never seek help because they have been told that there is nothing to be done beyond taking "a few aspirin." Hundreds of millions of dollars are wasted annually on quackery-type treatments because people are unaware that arthritis can be treated even if not cured.

P. L. 93-640, fully funded, would be much less expensive than the cost to the nation caused by arthritis in a single year. Only the common cold causes more lost workdays. Many are like I am: too disabled to work.



It is still a shock to me to realize that I am actually a disabled person. When I find that I cannot walk my dog around the block once a day without causing painful inflammation in my knees, or touch up a few wash-and-wear garments with an iron without feeling faint, I am made very aware of my limitations.

I have been asked where I have arthritis. I have rheumatoid arthritis all over my body. For months I had an elevated temperature. I believe every joint has had its turn as the problem area. I understand what inflammation means: it means hot like in flame. Joints actually feel hot. The pain is beyond comprehension unless experienced.

My kind and loving husband has provided me with a heated indoor pool to exercise my joints without strain. I hope the National Arthritis Act can provide more therapy centers for people who cannot have such a private luxury.

I am the fourth consecutive generation in my family to have severe rheumatoid arthritis. I do not believe I could endure the grief if it were to strike my handsome, athletic son, a captain in the United States Air Force.

Like millions of other arthritics, I want to be well. I want to be the kind of wife my husband deserves, and return to the life of a productive member of society. For all arthritics everywhere, and their families, I implore you to work unceasingly for the research that will bring an end to this scourge to mankind.

ENGLEMAN: Thank you very much, Mrs. Hesser. Dr. Dörner.

TESTIMONY OF  
ROBERT W. DÖRNER, Ph.D.  
ASSISTANT PROFESSOR OF  
BIOCHEMISTRY AND INTERNAL MEDICINE  
DEPARTMENT OF INTERNAL MEDICINE  
ST. LOUIS UNIVERSITY SCHOOL OF MEDICINE

DÖRNER: I'm Bob Dörner. I'm an Assistant Professor of Biochemistry and Internal Medicine at Saint Louis University. I'm a Ph.D. in biochemistry, working on arthritis research in the section on arthritis.

Ladies and gentlemen, the National Arthritis Act has created momentum towards conquering the various forms of arthritis, and I urge you to follow through decisively. I realize that in an election year, particularly, the temptation for our lawmakers is great to devise a highly visible and politically opportune program of providing token aid to every one of this country's 16 million arthritis sufferers. This will not conquer arthritis, and we certainly do not need another white elephant in the health sector. Instead, I urge you to devise a sensible, low-key program devoting most of our resources to research, both clinical and basic science, and lesser but important percentages of our resources to physician education and patient care.

If I may use basic research in the area of rheumatoid arthritis, with which I am most familiar, as an example, one could state, perhaps a little simplistically, that three questions need to be answered, to wit: What causes rheumatoid arthritis? How does the disease perpetuate itself? How is connective tissue damage caused?

The cause of rheumatoid arthritis is, of course, quite unknown, and a specific program to answer question one is not presently feasible. However, I would hope that we would find it possible to recognize and fund imaginative new approaches to the problem. The mode of perpetuation of the disease appears to be by immunological means, and connective tissue damage is, of course, ultimately biochemical. Thus, areas of research most relevant to the arthritis problem, in addition to clinical research, are immunological and biochemical research. In each of these areas a minimal research project in a medical school setting could be supported for \$30,000 to \$40,000 a year.

The second priority in a rationale antiarthritis program should be physician education. The need here is twofold: firstly, we need national arthritis fellowships to train young physicians to become first-rate rheumatologists. The second aspect of physician education deals with the education of primary care physicians typically in rural areas, and is inseparably linked with patient care in rural areas. While arthritis patients who have access to major medical centers and their multidisciplinary arthritis clinics generally receive adequate treatment, this is frequently not the case for those patients located in outlying rural areas. To solve these problems, our institution has experimented with a system of visiting consultant teams who at the same time provide physician education and patient care and referral facilities to the University Hospital. As a result, it appears possible to provide excellent patient care to all arthritics in outlying areas, provided that funds can be obtained for such a system.

So far I have dissected the needs, as I see them, in terms of research, education, and patient care. In reality, however, these functions are intertwined and mutually enhance and cross-fertilize each other. Consequently, I would like to suggest that a quantum unit of arthritis support be defined as support for one clinical research project, plus one basic science research project, plus one arthritis fellow, and that one such quantum unit be placed in each medical school with a rheumatology program and that it be funded and assume responsibility for a referral system among the primary care physicians in its hinterland.

Thank you.

ENGLEMAN: Could you put a dollar figure on that point?

DORNER: As it came out of earlier testimony, a fellow, at the present time, costs something like \$13,000 a year. I would imagine that supporting facilities for the fellow could be made accessible from the two research projects that I'm talking about here at \$35,000 a year. So we are talking about something on the order of \$85,000, plus the money that it would take to outreach to the outlying areas. I really don't have a

good figure on that. I've worked on this as a result of a previous grant application.

ENGLEMAN: May we hear from Robert Muench.

TESTIMONY OF  
ROBERT MUENCH  
PATIENT, ST. LOUIS, MISSOURI

MUENCH: My name is Robert Muench. I am a diabetic, and also I have rheumatoid arthritis.

The problem which confronted me as a result of rheumatoid arthritis, diabetes, and complications, was proving that I was disabled, according to the terms of the Social Security Administration. I applied for total disability benefits and was denied because the administration stated my illness was not disabling. I then applied for a review and was again denied. This application took almost 1 year to process. I then asked for a review by an administrative law judge, which is the next appeal step under the terms of the law. It was almost 9 months before the hearing was granted. At the hearing I was allowed to review the evidence compiled by the administration, and learned that the doctors who were employed by the administration stated in their report that I should be entitled to full benefits under the law. The administrative law judge then reversed all previous findings and awarded a partial claim.

During this 2-year period in which my application was pending, I attempted to earn some income. Because my earnings were over \$140 per month, the administrative law judge determined that I was not eligible for future benefits. The amount of benefits awarded was not properly determined and, to correct the error, I was requested to appeal to the Appeals Council in Washington, D.C. for another hearing. This hearing then corrected the error made by the administrative law judge. The total time required for this procedure was almost 2 1/2 years. This happened at a time when financial problems became insurmountable and had far-reaching effects upon other members of my family which consisted of three teenage children. The entire procedure for disability claims under the present Social Security program needs considerable improvement. In the short run, immediate steps could be taken to shorten the length of time allowed the administration to process a claim. A span of 2 1/2 years is totally unreasonable.

At the present time, my average medical expenses are almost \$100 per month. These were not covered by Medicare and have become a great burden. Congress can help a disabled person. They have passed many welfare-for-the-rich programs. It is time for them to develop programs for those who have a true need.

While my claim was being processed, some of the things that came to light are as follows:

- (1) The Social Security Administration ignored advice from their own investigators.



- (2) I was advised that most claims for disability for short term periods were almost always automatically rejected by them.
- (3) Those responsible for making decisions in handling my claim erred in their judgment and did not understand the Social Security law, the proof of this being that, in the end, all of their findings were reversed.
- (4) Although the U. S. Government, in effect, held up monies due to me for over 2 years, no interest was due to me as a penalty. As a result, they have nothing to lose by holding up a claim or delaying the process of the claim.

Thank you.

ENGLEMAN: Did you want to make any specific suggestions as to what we can do to alleviate this problem?

MUENCH: I realize that this is probably out of your area. I do advocate, though, that research be predominant when you're making your decision as far as the allocation of the funds that you have available. I do feel that the medical profession has given me great assistance and has done a very good job in handling my case. Only further research can improve treatment for the rheumatoid victims.

ENGLEMAN: Elmer Matyi?

TESTIMONY OF  
ELMER MATYI  
PATIENT, ST. LOUIS, MISSOURI

MATYI: My name is Elmer Matyi, and I reside here in St. Louis, Missouri.

During World War II, I served in the United States Army. As a result of action in combat, I sustained severe injuries to my knees. I was thrown from a halftrack during an operation in the Philippines. Along with my knee injuries, I sustained a neck and a head injury. I subsequently was discharged, honorably, after the war with a 10 percent disability.

In 1955, I entered a V.A. hospital for additional treatment to my knees. However, due to illness within my family, I had to return to my home in Illinois. During this short stay in the hospital, I was diagnosed as suffering from a broken kneecap, right knee.

I continued working, but in the early 1960's my neck began to give me severe headaches and other serious problems. I was treated by my private physician, Dr. H. T. Duffy. In the early 1970's my knees began to give me a great deal of problems; so much, in fact, that I could hardly perform my job requirements. I returned to the V.A. hospital in St. Louis, and was treated by Dr. Cook of the V.A. staff.

In June of 1973, my knees were hurting so bad that I entered the V.A. hospital for treatment. It should be noted that I had informed the physicians at the hospital that I did not want my kneecap removed. An operation was performed on my right knee, and they, against my instructions, removed my kneecap. I was subsequently awarded a 20 percent disability from the Veterans' Administration.

I have, as a result of my knees, been unable to work. Due to the damage to my right knee, I put more emphasis on my left leg and, according to a physician's diagnosis, injured my left knee. This problem complicated matters even more by affecting my back.

I was never any better after receiving my operation. I was 100 times worse. I was, after therapy, supposed to be able to bend my knee from 15 to 60 percent. I cannot do this. Now my left knee is causing me extensive pain. I was treated at the LHI building, on Grand Avenue, and the attending physician advised me to take aspirin. I did this, 20 to 30 per day, but aspirin gives me a very upset stomach.

I feel that I deserve a reevaluation from the V.A. with an upgrading for 30 to 100 percent. I cannot perform any heavy work, and this is affecting my family situation along with causing me mental duress. The Social Security Administration has authorized a 100 percent disability pension for me. Why is there conflict between two Government agencies? I am disabled; there is no question concerning this.

There has been discrepancy after discrepancy among the Veterans' Administration regarding my injury. Every time that I contact them I run into some sort of bureaucratic boondoggle that causes unnecessary delays in my case.

ENGLEMAN: Thank you, Mr. Matyi. One of the agencies that is represented on this Commission is the Veterans' Administration. He just happens to be here today, Dr. Otchin.

MATYI: I'd like to say the same for the good doctor over there. I mean, when a man goes into Veterans' for arthritis, the first damn thing they want to do, they want to take out his kneecap. If it works, it's fine; but if it don't work, it's a hell of a deal.

ENGLEMAN: Would you suggest that we recommend to Congress that we stop taking out kneecaps?

MATYI: I recommend it.

ENGLEMAN: Dr. Otchin, do you have any additional recommendations you would like to make?

OTCHIN: I'm afraid that any comments I have will really not be of great benefit to you. I'm sure from the tone of your letter that you probably encountered certain resistance to your claims within the Veterans' Administration. We do have a fairly complicated bureaucratic separation between the Department of Medicine and Surgery, which is responsible for providing medical care, and which, in your case, it sounds

like you have some concerns about, and the division that actually adjudicates claims and awards disability pensions, and so forth.

All I can say is that there is an appeals mechanism that extends to several levels above the initial decision. If you're dissatisfied with the decision made in your case, I would certainly encourage you to pursue it to the highest level, including the central office in Washington. Obviously, I can't say anything in response to the particulars of your case.

POLLEY: Dr. Otchin, I'd just like to let you know that ordinarily he picks on the Mayo Clinic.

FELTS: I would like to respond to this group's presentation, to some extent, to let them be aware that the Commission is aware of a number of areas of problems in this entire area. The entire question of compensation or maintenance for individuals who are disabled and partially disabled by the American society is a very difficult issue. It involves allocation of resources in areas that many times are considered and classified to be social overlapping medical. It is an area where resources are limited. I really don't believe that our society has come to grips with this or has come up with final answers in this entire area. It continues to be a moving target. Any information like this that we can accumulate on our tours around the country that's factual and helps focus in on the major, identifiable detriments to assistance can be most helpful.

In Mr. Muench's presentation, I had a little difficulty, sir, in trying to assess where I thought a diagnosis should be placed on your problem. I was wondering, is this really a fault of medical criteria in the determination of disability, the presence or absence or the percentage? Is it a fault of the legal process, a course of law, an inequity of law, that needs to be addressed legislatively? Is it simply a series of mishaps, if you would, in the implementation of good criteria along both lines?

I think that as long as humans are implementing these things there are going to always be a certain percentage of mishaps along that line, and, hopefully, the system will allow for correction. But I really couldn't be sure which of these three categories one should address in your presentation.

MUENCH: Let me try to answer your question or clarify the point. When I initially applied for Social Security disability benefits, the file was turned over to the State of Missouri for investigation. The State of Missouri then reviewed my case and requested a complete medical examination at their expense and by their doctors. I took their medical examination, and the doctor wrote the report to the Social Security Administration. He reported that I was, in his opinion, entitled to full disability benefits under the law. The office in Baltimore of the Social Security Administration then wrote back to me that I was not totally disabled. Does that answer your question? They came back with the statement that none of my major joints were impaired, which is not normally the case under rheumatoid arthritis.



FELTS: I think I would react that I would regard that as an implementation problem.

MUENCH: And it just kept being continually mishandled.

ENGLEMAN: We have one more witness in this group that we would like to hear from, Victoria Dry.

TESTIMONY OF  
VICTORIA DRY  
EASTERN DISTRICT  
MISSOURI PHYSICAL THERAPY ASSOCIATION

DRY: Thank you. My name is Victoria Dry, and I'm here representing the Missouri Physical Therapy Association. On behalf of that association's membership I would like to ask this Commission to report to Congress that the physical therapists in Missouri really do favor adequate appropriations for the National Arthritis Act.

I'm not going to repeat statistics nor moving, personal stories about arthritis and how it cripples Americans and how it causes suffering, loss of independence, and loss of productivity.

Instead, I urge you to ask Congress to grant appropriations for the National Arthritis Act so that our elected legislators can define our American society as a society which sets its priorities according to humanistic principles. I hope our legislators will define us as a nation of people committed to dealing with the practical problems of our citizens. I remind you that Neil Armstrong and "Buzz" Aldrin have left man's footprints on the moon. I think this means our society can do almost anything it makes a national commitment to do. The physical therapists in this area hope we'll make a national commitment to cure arthritis. Some of the specific things we hope that your National Arthritis Plan will ask in Congress are:

- (1) Programs for early diagnosis by routine screening in our schools, and also availability of physical therapy services in our schools.
- (2) Expansion of rehabilitation services so that these services can be more accessible to the population, particularly on programs such as mobile units of rehabilitation teams so that the knowledge we do have can benefit those Americans who are in the more rural areas of the country.
- (3) Development of specialized training in the management of arthritis for our physicians, nurses, and allied health professionals.
- (4) Special provisions for older Americans with arthritis so that they can receive rehabilitation services in their homes.

This latter point is most immediate to me because I deliver home care services to people with arthritis, and I see every day how much independence they lose. I think our older Americans really deserve everything we can do to make sure that they keep their independence. Perhaps in 1976, when we commemorate the 200th anniversary of the Declaration of Independence, millions of Americans will gain personal independence through victory over arthritis. Thank you.

ENGLEMAN: Thank you, Ms. Dry. Are there any questions from the members of the Commission of the group of witnesses? Dr. Lamont-Havers.

LAMONT-HAVERS: I really couldn't let Mrs. Hesser go without asking her when did she get her arthritis and on what side of the family?

HESSER: From my mother's side. My mother is now in a nursing home with severe rheumatoid arthritis. My earliest memories are of my grandfather in a wheelchair with rheumatoid arthritis. My mother recalls that his mother was also in a wheelchair from rheumatoid arthritis.

LAMONT-HAVERS: When did you get rheumatoid?

HESSER: Four years ago. At least it became pronounced to the point they diagnosed it.

LAMONT-HAVERS: Mr. Chairman, I would like to commend to you Dr. Dorner for his commitment to research in arthritis for about 15-odd years now.

ENGLEMAN: Thank you. It's been a pleasure to have you here. Thank you very much. We will now call on Donna Holsten.

TESTIMONY OF  
DONNA HOLSTEN, M.S.P.H.  
ARTHRITIS PATIENT EDUCATOR  
ARTHRITIS CENTER  
UNIVERSITY OF MISSOURI-COLUMBIA

HOLSTEN: My name is Donna Holsten, and I am a health educator at the University of Missouri-Columbia Arthritis Center. I am also an arthritis patient.

As you've heard before, arthritis is not a disease of the aged; children and young adults are also affected. I have had juvenile rheumatoid arthritis for 15 years. I was 10 years old when I came home after school one day with all fingers on both of my hands swollen and painful. From that time on, I have been hospitalized many times, taken numerous medications and had physical and occupational therapy and surgical procedures for my arthritis.

Fortunately, much of the expense was picked up by third party payers. The emotional support provided by the physicians and allied health professionals was very helpful to me and my family. Their encouragement enabled me to attend college and obtain a master's degree. However, some

arthritis sufferers are not as fortunate as I. Because of inadequate insurance or ineligibility for aid, the financial burden falls onto the arthritis sufferer and his family, leaving little to live on and for vocational training. Others do not come in contact with physicians and allied health professionals trained to deal with the problems of arthritis sufferers. There is a need for additional health personnel trained in rheumatology, as well as financial support for medical expenses of arthritis sufferers.

As a health educator, I am concerned about educating patients, their families and the general public about arthritis. An arthritis patient must live with his disease for the rest of his life. Therefore, he requires instruction about his disease process, how each treatment can help him and why he must faithfully carry out his home treatment program. He also needs encouragement and support during trying times. His family needs to understand the patient's arthritis in order to lend aid and support when most appropriate. The public must be informed not only about the seriousness of arthritis, but they need to know that with available treatment one need not look forward to a life as a cripple and to be aware of many other myths about arthritis. I feel that educational programs supply this information as well as promote understanding of arthritis and provide emotional support to the arthritis sufferer.

At our arthritis center we are attempting to determine if this is true by evaluating the center's patient education program. (See Appendix I and II.) We have found a significant increase in knowledge of arthritis after exposure to the educational program. Patients have felt themselves to be more knowledgeable and are less anxious about their diseases but felt that neither their general outlooks nor their families' understanding of arthritis changed much. The design of the evaluation instrument appears to be very important since some standard testing formats appeared to confuse many of our patients. Much more research needs to be done in order to develop effective educational methods which produce beneficial behavior changes in arthritis patients.

In summary, I ask the Commission to consider the following recommendations among high priorities:

- (1) Support of educational programs for arthritis sufferers, their families and the general public. This includes support of existing patient educational programs, the development of new educational programs, and provisions for developing effective techniques for evaluating these programs.
- (2) Support new and existing training programs for allied health professionals in rheumatology. More of these professionals are needed to provide education, treatment and emotional support to a greater number of arthritis sufferers.
- (3) Financial support to the arthritis sufferer either directly or through third-party payers earmarked for medical and/or vocational training expenses.



APPENDIX I

- D. Holsten, A.C. Morris, W. Gaunt, and M. Moeschberger, "Relative Effectiveness of Arthritis Patient Education Programs," Clinical Research, University of Missouri, Columbia, Mo.

Abstract: Traditionally, patient education has taken the form of brief discussions between patients and physicians or other health personnel. Patients may learn about their disease but not be motivated to change their behavior and follow therapeutic programs. Attempts to measure effectiveness of this approach have been rare. We have compared the effectiveness of patient education on a special multidisciplinary arthritis center (AC) with that on the general (G) wards. A questionnaire was used to assess changes in knowledge, attitude, behavior and physical capabilities as reported by patients at an average of 6 months after discharge. Patient knowledge was also directly tested. Forty-two AC patients were exposed to an education program involving individual, family and group discussions and specially developed written materials. Education of 15 G patients varied widely. AC patients felt themselves more knowledgeable about arthritis and scored higher on the knowledge test (means: AC=79%; G=66%) after hospitalization. Symptomatic improvement was reported by both groups, but ability to rest and pain relief were improved more in AC than G patients. Pain interfered less with daily activities in both groups. Patients who understood aspirin and heat treatments were more likely to use them correctly, but knowledge and use of rest or exercise were not correlated. Teaching and testing techniques were both felt to need refinement. Our findings suggest 1) Hospitalization of arthritis patients results in symptomatic improvement 2) An organized educational program is more effective in improving patient knowledge of arthritis than the approach generally used and 3) Better patient understanding of specific therapeutic agents can probably lead to their better use by patients.

APPENDIX II

D. Holsten, A.D. Morris, and M. Moeschberger, "Effect and Evaluation of a Patient Education Program," Clinical Research, University of Missouri, Columbia, Mo.

Abstract: The goal of patient education programs is to increase compliance with treatment programs by increasing knowledge of arthritis and changing patient attitudes. To test the validity of this approach we have investigated the effect of hospitalization on a multidisciplinary arthritis unit on patient knowledge and behavior. A questionnaire assessing knowledge was given on admission to 25 patients. These patients were then exposed to an organized patient education program consisting of individual, family, and group discussions as well as demonstrations and visual aids including films and reading materials. One week postdischarge an identical knowledge questionnaire plus another questionnaire assessing patient background, attitudes, behavior and physical capabilities before and after hospitalization was mailed to each patient. Twelve were returned. A significant increase in knowledge ( $P < .021$ ) was found after hospitalization. Patients also felt themselves more knowledgeable and less anxious about their diseases ( $P \leq .004$  in both cases) after discharge and pain decreased after hospitalization ( $p = .016$ ) while functional levels improved ( $p = .03$ ). Understanding of disease by families and general outlook by patients didn't seem to be significantly changed. The design of the questionnaire appeared to be important since some standard test formats appeared to confuse many patients. Directions were frequently not followed, especially with multiple-choice questions. Our findings suggest 1) an organized educational program can increase a patient's knowledge about arthritis, 2) hospitalization can result in symptomatic improvement and 3) testing techniques must be especially adapted for patient populations.

ENGLEMAN: Thank you, Ms. Holsten. Are there any questions from the Commission?

SHIELDS: I was wondering what your feelings are regarding the patients, whether you think that the patient is better informed than to have spent less time taking classes in methods, say, within the medical community, or do you think it makes much difference?

HOLSTEN: Yes, I feel this is true. The better someone knows about his disease, what it can do, et cetera, that these are the right treatments, and these are the things that can help him, I feel that he'll be more likely to stay with the treatments. There are a few that won't, but I think most of them will.

SHIELDS: Is your research trying to answer that question? That's a lot of money. I think it was stated to the extent of \$400 million is spent on classes a year, and that, of course, needs to be covered.

HOLSTEN: What we're trying to do is determine whether knowledge really does help the arthritis patient continue with his (inaudible) and continue with his treatment.

FELTS: Donna, I'd like to ask, have you been totally disabled at any time during the 15 years?

HOLSTEN: Not that I recall. I've just been in and out of the hospital. I've had lots of pain, but I've never really been totally disabled.

FELTS: I think you should be commended for what you're doing.

HOLSTEN: Thank you.

MELICH: I'd like to ask you how you started in this particular profession? How did you get your training? I know your interest is there, but how did you actually get started, knowing how to go and where to go to get it?

HOLSTEN: I came about it in a round about way. My undergraduate degree is in social work. I was just actually talking to someone who was in public health, and they asked me what my interests were. I told them that I was interested in health, etc., etc., and they said, "Well, why don't you try public health?" So I explored the Department of Community Health and Medical (inaudible) at the University of Missouri to see what they had to offer, and they had community health education. Therefore, they talked to me about education of people about their health, and because there is an arthritis center located there and one of my faculty members talked with Dr. Sharp, I was plugged into the arthritis center as a student, and then I worked there.

MELICH: Are you the only one doing this particular thing right now in a training capacity?

HOLSTEN: I am not training, I am working.



MELICH: I mean, do you have other people that are studying to do the same thing you are, that you know of?

HOLSTEN: Do you mean arthritis, particularly?

MELICH: Right.

HOLSTEN: There is no one that I know of at the moment. Hopefully, I can influence this year's class to get involved in it.

VOICE: May I ask you if you are satisfied with the teaching material that you now have for patients? If not, what do you want?

HOLSTEN: You really shouldn't ask me that question. The stuff that's available commercially, of course, is from the Arthritis Foundation. I feel like for our patient population, which has an educational level of about sixth to eighth grade, it's too high for them. Using a testing technique, it's 12th grade, the literature is. So we at the arthritis center have developed our own educational materials, and, hopefully, they're written around the eighth grade level. They also give more details about the disease itself than the Arthritis Foundation stuff does.

ENGLEMAN: We will now call on Mr. Tull.

TESTIMONY OF  
ROBERT TULL  
SECRETARY, EASTERN MISSOURI CHAPTER  
ARTHRITIS FOUNDATION

TULL: Mr. Chairman, ladies and gentlemen of the Commission:

As a victim of rheumatoid arthritis, and as Secretary of the Arthritis Foundation of the Eastern District of Missouri, I feel that I can speak with a great deal of firsthand knowledge of the serious needs for funding under the National Arthritis Act.

As background information, and a little bit about myself, I have had surgery on both knees for the insertion of a McIntosh prosthesis; I have had foot surgery involving the metatarsal arch; wrist surgery for a dropped little finger; total hip surgery involving the insertion of a Charnley-Muller prosthesis; and total knee surgery involving the insertion of a Buchholtz prosthesis. And I am still able to walk and do things necessary and essential to me in my profession as an attorney.

I feel that I have been one of the luckier ones. I have been able to afford this surgery through a well conceived insurance program, and I am more than thankful that the prosthesis and the techniques that are used in connection with them have become available before my need has arisen, even though in some instances the technique has been approved in the United States not more than 6 months before my need for surgery has become immediately necessary.

I have been a member of the Arthritis Foundation Board of Directors of the Eastern District of Missouri for a number of years, and I am now Secretary. Through this program, I realize our serious inadequacies from a financial standpoint. Having participated both in individual drives and through the United Fund programs, I understand the difficulty at all times, and particularly in these times, of raising funds. Having thus viewed the arthritis program from these different approaches, I know the need for the funding of this program.

On many occasions I have been asked about the progression of this disease in my particular instance, and who is qualified to help with the problem that the individual with whom I'm talking is confronted. I know the serious shortage of trained rheumatologists able to give proper treatment of this disease. I regard it as a serious inadequacy of our medical schools that at least one-third of them are unable to provide any formal training in arthritis problems.

We, in my hometown of Columbia, Missouri, are more than fortunate to have one of the only 41 arthritis centers in the nation available which can provide team teaching and superior patient screening and detection of arthritis, as well as an extensive research program. All of these things are imperative if the serious results of this disease are to be controlled and stabilized.

To me, it is abhorrent that a country of our wealth and progressive approach does not underwrite a program which will attack this most far-reaching disease known to man. It is obvious that we who are interested in this program will not be able to raise sufficient funds to combat this disease on a scale befitting the serious toll that is taken in time, pain, suffering, and productivity. Failure to train doctors, to advance toward the cure of this disease through research, and to offer relief to these people suffering from this disease can only result in permitting its serious effects to multiply along with our increasing population.

I most earnestly urge this Commission to make known to the Congress of the United States the earnest and sincere feelings which these persons testifying today are making known to you. Thank you, and Godspeed.

ENGLEMAN: Thank you, Mr. Tull. We will now call on Carla.

TESTIMONY OF  
CARLA SCHENEWERK, O.T.R.  
CHIEF OCCUPATIONAL THERAPIST  
MCUNT ST. ROSE HOSPITAL

SCHENEWERK: I'm Carla Schenewerk, Chief Occupational Therapist at Mount St. Rose Hospital.

We appreciate your invitation to submit this brief summary of some of our thoughts on approaches to the treatment of arthritic patients. I am employed by Mount St. Rose Hospital, which is primarily a geriatric rehabilitation facility, fully accredited by the Joint Commission on Accreditation of Hospitals. Our summary includes our own thoughts and expertise as gained in the treatment of arthritic patients, as well as input from colleagues and other disciplines within the hospital.

We realize that the approach to arthritis needs to be handled on many levels, including continuing research, medical management, as well as care of these presently afflicted. Mount St. Rose Hospital presently treats the arthritic, although it may not be the primary diagnosis of the admitted patient. It is, however, the secondary and tertiary diagnosis significant enough in numbers to warrant our concern, consideration, and this presentation.

At present, it is our main concern that services to the arthritic be brought under a single umbrella of total care as can be made possible. To be specific, at present, Mount St. Rose offers to the arthritic patient a variety of services, including medical care, nursing care, physical, occupational, speech, and recreational therapy, social service, and dietary management.

It is our feeling that, through the work of the National Commission, our particular training be put to work in an expanded program of services to the arthritic patient, as well as to those serving him within the facility. We see within the range of those additional services such things as an outpatient program which would include all of the above, plus home care programs under the same umbrella, including all those present skills now operating, plus the addition of those thought needed. Included in our thinking about home care are such components as instruction in the activities of daily living, the development of avocational interests, the matter of kitchen adaptation, splinting, and so on. We see in addition an expansion into home care of continuing mobility skills, functional adaptation of architecture, and amplication of therapeutic modality, maintenance of strength and joint mobility.

We see within our present facility an opportunity for an in-depth look at inservice programs covering the patient, his family, and our own staff, as well as the community in general. Included might well be such areas of interest as the disease entity itself, its course, alternative treatments and procedures, and medications. We see a need for a home helper program, the possibility of a club for arthritics, and psychological counseling for both patient and family in individual and group settings. We certainly see the need for rehabilitation counseling, more vocational direction to both evaluate and refer for training the arthritic whom it is felt can



return to a productive lifestyle, and, for those who cannot, appropriate counseling and referral to those agencies capable of helping those designated as permanently and totally disabled.

We present this outline to the Commission with the full knowledge that some of the services presented are presently performed by a variety of health care agencies. Nevertheless, it is our feeling that less fragmentation and more centralization will result in a much more fruitful program in terms of continuity of care, cost containment, and cannot but benefit all affected; certainly, and foremost, the patient. We trust that as you go about your deliberations, that in the development of the concept of centers, as called for in the Act, you give serious consideration to thinking of such entities as providing a centralized information and referral service; as inviting and reviewing any and all proposals and accompanying budgets introduced by interested and qualified organizations; and, finally, that the centers function on the theory of purchase-of-service agreements with those agencies presently serving the arthritic patient. Thank you.

ENGLEMAN: Thank you, Ms. Schenewerk. Sister Suzanne Wesley.

TESTIMONY OF  
SISTER SUZANNE WESLEY  
SISTERS OF ST. JOSEPH  
CARDINAL RITTER INSTITUTE

WESLEY: I have been asked to prepare a public statement by my community, the Sisters of St. Joseph, and my agency, the Cardinal Ritter Institute, that would both underscore and support the need for increased funding to implement the National Arthritis Act that would make possible in time an eradication of the insidious disease.

I found myself hesitant and somewhat reluctant to accept the task because I, too, have rheumatoid arthritis, and have been diagnosed as such for over 3 years, during which time I have prayed, waited, despaired, and hoped again that someone would stumble on the answer that would restore my otherwise healthy body to a functional level.

One finds it difficult to talk to a group of total strangers about something that I have such a personal stake in. Looking at the task beyond myself, however, I began to feel the compulsion and necessity to make a public statement because I am a registered public health nurse with the responsibility for the health care of over 1,500 elderly residents living in senior high rise buildings, and probably all have been affected in some way by the disease of arthritis. I am also a consultant to nursing homes in St. Louis, where I continually see scores of victims of this dread disease, a disease that takes from these people some of their most precious gifts, those of mobility and independence; a disease that so often causes and creates a lack of understanding on the part of the observer.

My experience has been one that has shown arthritis not to be an exciting disease, not a disease that generally is going to cause a quick,

unannounced end to one's life; but rather a slow, painful, steadily increasing disease that little by little slows down, cripples, and eventually may incapacitate an otherwise perfectly healthy individual. This disease seems to me to be an insidious robber that takes over so completely the bodies of individuals that it sometimes breaks their spirits since the effort to remain independent and wait patiently for a cure becomes such a burden and chore for one in unmitigated discomfort at every movement.

I've often heard professional people, as well as the ordinary observer, reply or observe, "Well, he's getting old so he's bound to have arthritis. You just have to expect it these days." I remember the years that I, as a nurse, saw "arthritis" on a medical diagnosis but was caught up in what seemed to be the major problems of heart, lungs, etc., that I literally ignored what I now know may have been for the patients involved the most uncomfortable, painful, and frightening of all his medical problems.

Since I have the disease myself, I can attest to the fright, the pain, the feeling of uselessness, the feelings of aloneness and loneliness because my appearance often looks healthy to the ordinary observer while every joint in my body may ache or hurt. Even interested people misunderstand or forget that external appearance may not convey the true picture. Arthritis is not a glamorous disease. After the initial stages and the newness wears off, folks quickly forget how the arthritis victim feels and what he is experiencing. In a society that promulgates an ethic of personal worth as equal to the work one is able to perform, or his productivity, an arthritis victim may also have to deal with feelings of low self-esteem and a poor self-image.

As a once young, vigorous, energetic woman with an unusual amount of stamina to fight disease, to work hard, to pray, and to play hard, I appeal to you to do everything possible to make the isolation of the disease entity, the cure and rehabilitation for victims of this disease possible and probable for millions like myself and those for whom I care. Thank you.

ENGLEMAN: Thank you very much. Are there any questions from the members of the Commission?

LEWIS: I have one question to the attorney. You mentioned that you were able to finance your illness. You have good insurance. What type of insurance coverage do you have?

TULL: Mrs. Lewis, I think that basically my problem has been answered. In addition to Blue Cross and Blue Shield, which my wife and I have for our family, I have a major medical program that is provided through the Missouri Bar Association, and it has worked beautifully. My last surgery was a total knee, a year ago last month, and it worked fine for me. I was in the hospital 17 days. Over the \$5,000 level, it pays 100 percent, my particular policy, and I think I ran \$5,002.

ENGLEMAN: Any other comments? We are a few minutes early. This is a most unusual circumstance, but we would entertain comments from those of



you in the audience who have not served as witnesses, comments or questions. Yes?

VOICE: I know you've done a lot of research, but what advances have you found which may be presented to the public to try to aid these people, from a nutritional standpoint, to help themselves? I'm not talking about curing the arthritis, for instance, but aid them, from a nutritional level, so that they are getting the proper nutrients.

ENGLEMAN: The question concerns what is being done in terms of the nutritional needs?

VOICE: What's being provided through the health services and through your foundation for nutritional information to the mass of people, which is great, really?

ENGLEMAN: We're not sitting here on behalf of any foundation. We are here essentially as a commission which will make recommendations. But we do have a nutritional expert here with us, Mr. Shields. I'm sure that he will be happy to answer your questions.

SHIELDS: I don't know how a physical therapist becomes a nutritional expert. I think that one of the major problems we have, and it's been alluded to so many times, is the fact that patients are not kept informed about what they can do for themselves, and so they spend a good deal of time chasing butterflies or quack cures. I'm convinced, as others have suggested, that if we do a better job of informing them of what they can do, and the kinds of exercises that they can perform, and the importance of seeing their doctor and staying within the medical profession, and proper nutrition, then much can be done to prevent them from going off and spending a lot of money on quackery.

There is no evidence that I know of at this time that any particular type of diet would help them any more than the same diet that all of us should have. There's been a question on nutrition, and I'm sure that (inaudible) effects would perhaps be possible. But it's so important to inform patients as to what they can do for themselves to keep them from chasing these butterflies.

ENGLEMAN: I didn't call on Mr. Shields as a physical therapist. I called on him because he does speak as the allied health professional on behalf of the Commission. Yes, ma'am.

VOICE: About 8 years ago, because I have arthritis myself, I was told by a very qualified doctor that allergy does not play any part in having arthritis. All experiments to date, all research to date, indicated that that was so. I mean, allergy to food, or any other substances, or even allergy to your own body tissue. Since I was told that about 8 years ago, I am quite interested to know whether or not thoughts have changed in that regard. Is there research that indicates that possibly allergy may have something to do with having arthritis?

ENGLEMAN: We're very fortunate that we can answer your question because we have on our Commission a man who speaks for the Institute on



Allergy, and we will now ask him to make a comment, Dr. Gay, wherever you are.

GAY: Thanks a lot, Dr. Engleman.

The rheumatologists may want equal time to this answer. Both of these diseases, both allergy and rheumatoid arthritis, have an immunological basis. Immunologists represent the principal cutting edge of research in both arthritis and in allergy. I think you'll find that in allergy there is a specific group of immunoglobulins involved in the allergy reaction. The rheumatologists may want to comment on whether they find the same groups involved in arthritis. However, when one gets to the specific reaction, I believe that the advice you got from your physician is still good.

VOICE: I did not mean to demean this physician in any way because I have the greatest admiration for him. He was quoting what was his knowledge at that time. But what I was trying to tell him was that I had known for years that when I ate certain foods, within a very short time I suffered extreme joint and muscle pain and other symptoms related to the arthritis, which he acknowledged I had, and it became much worse when I ate those kinds of foods and I would become very ill. Therefore, naturally, I was curious to know if there was any foundation to the information I was giving him, and if you know whether or not there was research in that field because the reaction I was getting was definitely allergic, and it was happening, too, to my brother, who has terrible arthritis, and who's had two hip transplants already. He reacted in the same way. So we have two examples of the same thing.

GAY: Dr. Engleman, I'll defer to the rheumatologists to speak about the joint reaction.

ENGLEMAN: It just happens it's 1 o'clock. On behalf of the Commission, I want to extend our appreciation to all of you for your very kind attention.

S U B M I T T E D S T A T E M E N T S

EMMA D. DAEHN  
St. Louis, Missouri

October 31, 1975

Being a senior citizen in my seventies I am starting to be bothered by arthritis in my right knee, notice it when going up or downstairs, also when sitting several hours such as dining out or playing cards. I have to push myself up by the arms of the chair. I noticed too that several of my friends remarked how stiff they were getting.

On a recent trip by bus to New Orleans on an AARP convention, after riding for two hours or more I could hardly get up and was stiff in my legs, so much so that it took several minutes walking to get limbered up again.

CAROLE HILL  
Barnhart, Missouri

October 31, 1975

My name is Carole Hill and I am 33 years old and for the last nine years I have suffered from the grueling pains of arthritis. I have a very helpful and understanding husband that doesn't pity or feel sorry for me and three beautiful children ages 13, 12, and 6 and I thank God for them and all the help they are to me because without them it would be very difficult to go on.

At first I didn't know how awful arthritis was, but after the first year I could have told people that the only way to describe it is that it is a living hell and I wouldn't want anyone to have to live with it.

Mine started with fever and pain in my wrists, and traveled from one joint to another affecting most all of my body. Only after a lot of expense and going to several doctors did they put me in the hospital and diagnose my case as rheumatoid arthritis.

The doctor there wanted me to stay in the hospital for treatment but by then I just couldn't stay away any longer from my family who needed me.

I came home and took 12 to 25 aspirin and 3 or 4 Indocin a day and tried that for a while but was still in such pain and misery and was suffering too much to keep on trying to drive back and forth to the doctor and very little money to spend on myself.

At the time I couldn't dress myself and, just to open and close my swollen hands, I would have to run hot water over them and try to exercise them to keep on going throughout the day. I cried most of the time.

Here I was only 24 years old--a young woman, and all my friends and neighbors my age were enjoying life and here I was so miserable and I couldn't understand why this was happening to me and why I couldn't do all the things they were doing.

In desperation, I decided, "I'm not going to give up", so I called the Arthritis Foundation and they were so very nice to listen to my problems. They told me of the closest hospital with an arthritis clinic--St. Louis University Hospital; I think that call was a lifesaver to me. If I hadn't gone there I might very well be crippled today.

I went to the arthritis clinic and was very fortunate to see Dr. Zuckner who I think is a great doctor and have continued going to him for the last 8 years.

It didn't take him long to tell me what I had and that I would have to come every week. They took X-rays, blood tests, and tried several different medications; none seemed to help a great deal.

He then decided to try gold shots which meant I had to drive 50 miles roundtrip and would have to go every week for approximately 30 weeks. In addition to the gold shots, I took Darvon and aspirin for pain and an exercise program for at home. I think the gold helped the swelling in my joints but they had to discontinue them because I found out I was pregnant and had to stop all medication.

I continued to go to the clinic and realized the whole nine months of my pregnancy my arthritis went away. I was so happy. If only it could have lasted. Almost immediately after having our third child did the fever return in my hands and had to be packed in ice.

I was so discouraged because I thought my arthritis was gone forever. Once again frequent trips to the hospital, only now it was worse because not only did I have arthritis but a new baby that needed my love and care, and just changing his diaper was horrible pain for my hands. I was so afraid of dropping him because I was losing my strength in my hands and arms and all my joints were aching again.

For relief the doctors would give me shots in my knuckles, wrists, and elbows, knees, and drain my knees when they needed it and then I'd have to try and drive home.

If there would have only been a program where people like myself and older people with arthritis or children with juvenile arthritis could have been transported to and from the hospital, or someone that could have come into the home to help bedridden patients to get their medication, treatment, and physical therapy. Home devices to make things a little easier and maybe some way to help with heavy housework that I can't do myself. And funds to make arthritics feel socially that they are still productive citizens by meetings and get-togethers possibly for people like myself, because at times you just feel like giving up.

I now go to physical therapy once a week trying to drive 28 miles one way to one hospital and still to the clinic every three weeks, but I don't know how long I can continue to drive. I have crutch grips on the steering wheel and a pencil aid to help me write this letter to you, which has been extremely painful, also splints for my hand to sleep in and orthopedic shoes to walk with.



St. Louis, Missouri

November 11, 1975

I take 10 or 12 Tylenol, 4 Darvon, 2 Prednisone, 2 iron pills, and Maalox just to get through the day. There are so many things I would like to do if able. I've tried fundraising this year and would like to continue to do other things to help, even if only to try to encourage others, because I know what they're going through and we can't give up.

I hope some of these things can be done by the National Arthritis Act and I want to thank you for listening to my story.

EUGENE PERLMAN  
St. Louis, Missouri

October 29, 1975

Please accept this letter to advise you that I want to testify and give testimony of my arthritic condition at the National Arthritis Commission at the Busch Memorial Center, St. Louis, Mo., on Tuesday, Nov. 11, 1975.

Originally, I suffered from periarthrititis (both shoulders) since 1971. I am now disabled and unable to drive. The disease has now spread to massive spinal osteoarthritis. Spinal surgery has been canceled as my knees are affected. My neck has only 20 percent motion. I am in need of transportation to an orthopedist and a neighborhood area for treatments. Since I left the hospital in Hot Springs, Arkansas, on May 21, 1975, I have not had any treatment. The change of weather in this area will cause discomfort and I will be hospitalized.

People like myself are in need of transportation and physicians who charge reasonable fees. It is impossible from this area to travel frequently as outpatients to a hospital that has adequate equipment and licensed physical therapists.

I hope to have the pleasure of testifying before your members on the difficulties that I experience in daily life from this disease.

JAMES H. BROWN  
St. Louis, Missouri

November 11, 1975

My name is James H. Brown, age 48, a graduate engineer, Vice President, Corporate Affairs of the St. Louis-San Francisco Railway Company, and a resident of St. Louis, Missouri.

My wife, Eleanor Brown, age 48, died last August of renal failure resulting from systemic lupus erythematosus and the complications resulting from other diseases she encountered as a result of reduced resistance caused by heavy dosages of steroids over an 11-year period.

Eleanor's health problems became apparent in 1960, primarily manifested by food allergies and tissue swelling. Four years and five physicians later, her disease was diagnosed as S.L.E., which settled in her kidneys.

Subsequently, in 1966 she contacted salmonella within her bloodstream and had to be desensitized in order to withstand the only available drug to which she was allergic. She went through the Mayo Clinic in 1968 and 1970 in order to seek relief of certain allergies, and hopeful of reducing the amount of steroids, which was partially accomplished. In 1972, oral surgery was performed on some abscesses. In May, 1974, she had a fibroid tumor removed and a complete hysterectomy. On April 30, 1975, due to swelling in the left hand and left foot, it became apparent histoplasmosis bacteria was in her system. She was treated with intravenous injections of Amphotericin B to the extent of 976 milligrams over a 12-week period. When its toxicity virtually eliminated kidney function, it was decided to transfer her to the University of California-Sacramento Medical Center for intravenous injections of Myconazol, which had been proven effective for the treatment of coccidioidomycosis. After five weeks, during which several complications developed, that is; increased allergies to various drugs, an abdominal infection, herpes zoster, nausea, three weeks on a respirator due to lung congestion, the requirement of peritoneal dialysis, peritonitis, three cardiac arrests, D.I.C., and Pseudomonas, she died on August 24, 1975. Preliminary results of the autopsy examination indicate an absence of any histoplasmosis bacteria within her system.

My wife, a graduate economist, was very positive, inquisitive, stuck to the rules, and persevered in everything she did with an extremely optimistic outlook.

While neither of us had any medical care training, our 11-year experience, seven hospital confinements at some of the best facilities in the nation, our exposure to more than 50 physicians' many of whom became close associates, reading everything published on the disease, talking with many other S.L.E. patients, and keeping a personal diary of the events as they have transpired, my conclusions as a layman are as follows:

- (1) Since the cause, as well as any effective means of preventing organ damage is not known, insufficient research has been performed in S.L.E.

- (2) Since the only therapeutic agent is cortisone, and it is known to lower the body's resistance to attack by other infections, much must be done to learn how to treat S.L.E. effectively without bringing on these other diseases that the S.L.E. patient's lowered resistance has difficulty withstanding.

In summary, I am most grateful to all of the physicians and other medical personnel for the extreme dedication and vigilant care given throughout my wife's treatment period; however, present and future S.L.E. sufferers deserve:

- (1) Better education of all physicians about this disorder to provide earlier diagnosis.
- (2) More trained rheumatologists (only about 2,000 in the U.S. today) skilled in the care of lupus patients.
- (3) Greater amounts of laymen-oriented materials for greater patient and public understanding of the disease.
- (4) Increased research to find the cause of S.L.E., and then treatment procedures and agents that do not create other devastating body problems.

It is my earnest request that you seriously consider utilizing some of the money appropriated by Congress, under the National Arthritis Act, for the above stated dire needs. The local Lupus Foundation and the local Arthritis Foundation desperately need your help.

Thank you for the opportunity to present my views.

ROBERT BEAKLEY  
St. Louis, Missouri

I am grateful to the members of the National Arthritis Commission for allowing me, a concerned citizen, the opportunity to speak today. I speak not as a patient, but as a member of a family, one of whom is a victim of systemic lupus erythematosus, a connective tissue disease believed to be closely related to arthritis. It is thought that a cure for one will bring about a cure for the other.

I feel that I, in a small way, represent not the half a million or more stricken with lupus, but the two and a half to three million people who comprise their families. The lupus patient, like the severely affected arthritis victim, poses problems not only for themselves but also for their family and friends.

Often the lupus patient has spent months, sometimes years going from doctor to doctor in an effort to obtain help. Frustration and doubts grow, and sooner or later the patient and family come to think that all of the aches and pains may be imaginary. When the patient is finally diagnosed and told that he or she has a chronic, possibly life-threatening disorder, the patient's first reaction is one of despair. Often the



doctor can't or won't take the time to fully explain the disease and alleviate some of the patient's fears.

If the lupus victim tries to find out more about the illness and goes to the library, the information most often found tells that lupus is invariably fatal. This information is completely out of date, but this is what many, many patients find. The frustration and depression which follows is inevitable. The stress and worry actually aggravate diseases such as lupus and arthritis.

I feel that several things could be done in the near future to alleviate the suffering of countless thousands in the years to come.

- (1) Lupus patients need much better informed physicians. We must have early diagnosis! More trained rheumatologists teaching in our medical schools would insure that our general practitioners are well versed concerning SLE.
- (2) We need more information about lupus written for the patient in layman terms to answer their questions and fears about this disease.
- (3) Low cost supportive counseling for the victim and family to help them to cope with this chronic and painful disorder.
- (4) Through better dissemination of new information on this disease give hope to the lupus patient that research will find the cause and cure for this disease. Confidence that research is progressing at a rapid rate would give a lift and brighten the outlook of all lupus victims.

RAYMOND H. VIETMEIER  
St. Peters, Missouri

#### Acupuncture vs. Arthritis

During the 6-year period of 1968 through 1973 I was either referred to or sent to 2 rheumatologists, 2 orthopedic surgeons, 2 general practitioners, 1 physiatrist, and 1 internal medicine doctor. All of them, except the internal medicine doctor told me I had ankylosing spondylitis, a form of rheumatoid arthritis of the spine.

Between August, 1972 and July, 1973,, I was on heavy maintenance doses of Butazolidin, later replaced with Indocin, Parafon Forte, Valium, Zylprim, plus Talwin for pain.

My work as a senior programmer gradually deteriorated and I found it harder to concentrate on extremely difficult problems. I am convinced it was the drugs that were doping me up and causing my performance to drop. I had to give up programming as a result.

In July, 1973, I was referred to a chiropractor who had been practicing acupuncture for 12 years. Within 3 weeks of 3 treatments per

week I was looking for a programmer's position again. I have had hardly any pain greater than minor, since then. That is almost 2-1/2 years of relief. However, I would like to emphasize that there are three factors involved in this fantastic recovery:

- (1) Maintenance acupuncture treatments at approximately 1 month intervals.
- (2) Improved diet. Little or no starchy foods, sugar or acid foods. This means cut down the consumption of bread, potatoes, tomatoes, pies, cakes, candy, etc.
- (3) Better rest. The physiatrist prescribed a hospital bed for me and I have found that by inclining the head about 20 degrees that morning stiffness and pain are significantly reduced.

One of the orthopedic surgeons Stated that I would be an invalid for the rest of my life and that he could only give me drugs to ease the pain. He said I would gradually get worse and that there was no known cure.

I was amazed when I think back to how my activities were restricted and I thought this was the way it would be forever.

To give you an idea of how well I have progressed, I bowled on a league last winter and only felt pain slightly sometimes the next morning.

ADELA R. SCHARR  
Florissant, Missouri

October 25, 1975

This letter may leave much to be desired because I am getting ready to leave St. Louis, Missouri, and shall not return until after your hearings there on Tuesday, November 11th. I regret this but hope this letter will suffice as a testimony to the care I paid for and received (?) during the twenty-six years I have had arthritis, all of which were spent in the St. Louis area with St. Louis doctors.

Fortunately, I have used an electric typewriter for over fifteen years or I should not be able to communicate with you by letter. My handwriting is now atrociously bad and I am unable to pound the keys of an ordinary typewriter enough to impress paper.

This is my story:

The knuckle of my left hand nearest the tip of the smallest finger became swollen first. I was working very hard at the time--about twenty hours per day--when it began. Within a month, the knuckle of the ring finger next to it became painful. I went to Dr. Macon (deceased now) who prescribed cortisone tablets three times per day. The cost was \$1 per tablet. I was only earning \$1,800 per year take-home pay, and was the wage earner as my husband was disabled and no one would hire him. With cortisone cost per year estimated as almost \$1,100, I knew I was faced with the impossible and would have destroyed myself except that I would not give up yet.

I left Dr. Macon's care, but before I did he diagnosed my illness as both rheumatoid arthritis and osteoarthritis. He thought the rheumatoid was due to six strep throat infections I'd had in four years. The osteo was due to an hysterectomy performed when I was thirty-seven years old (due to a bleeding sub-fibroid tumor).

Then I tried Barnes Hospital Clinic. The cost per visit was more than what a regular physician would charge me, but I got good advice along with treatment for other ailments that happened all about the same time. A doctor said to me, "Lady, don't waste your money. Take aspirin after meals, preferably with milk and never on an empty stomach. Be sure to eat leafy green vegetables and a well-balanced diet."

The doctor to whom I took my husband for hypertension soon after that said he'd help my arthritis. He said I had both kinds too. By this time, the small joints of my outer three fingers on both hands were throbbing, swollen, and painful. He injected a lot of something into the small fingers and it took away the pain in one. But the fingers have remained permanently crooked. He had the great idea that I needed hormone shots each month. I took Presnisone, I believe, and later he prescribed Indocin thrice daily.

Well, as time went on, more joints became affected. I asked about splinting. The doctor just shrugged that off. He didn't give me any advice about how to care for my arthritis, no admonitions, no anything. I continued to go to him because of my husband. I grew hair on my face. There were other bad effects of the combination of hormones he gave me. Attacks of colitis became almost constant. The doctor never gave any hint that the medicine he was prescribing could be causing this. I had a very hard job with many pressures and irascible bosses and I didn't dare quit work. When I complained at last about, not only a raw intestine, especially at the anus, but about all the flatulence in my abdomen, he said, "You can bottle the gas and sell it."

I could take no more of that doctor. So I called the Arthritis Foundation and it recommended an internist. (He is one of the officers.) By now I had some joints enlarged and hurting for over seven or eight years apiece and had suffered arthritis for fifteen years. It just kept progressing.

This new doctor saw to it that I had a complete physical examination. I was put on a bland diet and he said my intestine was "senile" and that never again would I be able to eat fresh fruits and vegetables. I didn't believe this, but followed a diet of baby food, etc., and got away from my work on a sabbatical leave for one year. He also prescribed Indocin without telling me about its side effects. He insisted that I use paraffin baths for my hands. I got just as good results with very warm baths in the tub every morning before going to work. The wax treatment was just a lot of bother to heat to proper temperature and it didn't last long enough each time. Getting away from pressures improved my intestinal trouble for the most part.

I couldn't stand this doctor although I went to him for several years. He had so many patients per hour that he couldn't take me for two hours



after the appointed time and then he only spent two to three minutes with me. It was a farce, and when he made me wait four hours before he saw me I stopped seeing him. It was too much wear and tear on me, so I asked around and another internist was recommended to me.

The new internist put me through a series of tests. He said I had osteoarthritis and all I needed to take was aspirin. But he wanted me to come back every two or three months. Whenever I had a cold and needed to see him or the other doctor who showed no true interest in his patients, he was too busy for that. Both could see a patient when that patient didn't really need a doctor but didn't want to see the patient when really ill. Isn't that ironic? One time I had a pain across my left breast and he did send me to get it X-rayed. It was evidently arthritis going across a rib from the sternum.

I had pains in the bottoms of my feet and told this doctor about them every time I went to him. He never said, "Take off your shoes and stockings and I'll take a look." Nor did he X-ray them. Finally, after a year and a half, I heard a surgeon on the arthritis program over radio station WEW and decided to ask him for help. So, what did I have? Four Martin's neuromas. And I quit going to any doctor for arthritis for over a year now.

Once before, I had thickening in my wrists and I saw a surgeon I'd heard on the program. He recommended an operation and I was tempted to have my wrists' senovial tissue taken out. But my husband had a stroke and no one else could care for him. So, I just prayed a lot and whenever my wrists hurt, as they do occasionally when I use them too much, I put elastic bands on them. That surgeon also said I showed only osteoarthritis because a latex sediment test didn't show the rheumatoid factor. He really believed I had rheumatoid arthritis, however.

Now, my arthritis spread while I was going to this last internist, who is also an officer of the Eastern Missouri Chapter, and has affected every finger including my thumbs. I have it in the neck, the other joints of the body, and have pains often in the bones, such as the shins. I had cramps at night in my legs and he gave me medicine for that. But just Vitamin B-6 does just as well. And I found lethicin and vitamin E made me stronger, although the doctors just poo-pooed the idea.

I have found out that some of my intestinal trouble was due to Indocin and it also affected my blood hemoglobin. And I can eat any kind of food now that I stopped taking Indocin the past three years.

The most help I have gotten was just by listening to the arthritis program on WEW. I took my husband to another internist within the year before he died and that man discovered what I had guessed. That my poor husband was suffering from ankylosing spondylitis and his doctor he'd gone to for twenty-four years hadn't even noticed the changes in my husband, although I called it to his attention!

Now, my testimony is this--that most of the doctors who profess to be rheumatologists aren't worth going to. They are only interested in making a fortune and not in their patients. I am sorry that fear of what

arthritis would do to me caused me to go to these so-called experts who could not halt or delay the progress on my body of this disease or even recognize it in my husband. If I were sure that there were a doctor in St. Louis area who could help me at all, I'd be glad to see him and obey his orders and take his prescriptions.

The surgeon who took out the Martin's neuromas mentioned several times to me that my "interesting" hands should be operated on and several finger joints could be replaced with plastic ones. Who is to believe that will work?

The need to find cures or respite for patients is tremendous. I hope it can be done.

JOSEPH ERGOVICH  
Raytown, Missouri

October 24, 1975

My name is Joseph Ergovich, I have rheumatoid arthritis. Dr. Richard Owens sent me for blood tests to Research Hospital and he called me at home and told me I had rheumatoid arthritis. I asked him if it was like the gout and he told me it was worse than gout. I was working at the Hawthorne Power Plant for two years and my feet and ankles were getting awful sore. I waited until the job ended in the last part of 1969. At that time I could not walk. My doctor sent me to the Veterans' Hospital where I stayed for one month. I was given cortisone and Dr. Trimble and Dr. Godfrey were my doctors. They started giving me gold shots which helped me for about 16 or 17 days. I was discharged and I had to go back every weekend four or five times for my gold shots. But it just kept getting worse. Dr. Trimble told me about the Arthritis Foundation and I say thank God for the relief they have given me.

When our government wanted to help in World War II, three brothers besides me went to the call. I was the only dummy that got wounded. That injury on top of my arthritis makes it very hard for me to live right. Our government should give us help. What I cannot understand is how the government can stand by and lose all the money it does for not helping the arthritics. It just makes sense to put in some money to train good people like they have at the foundation so people like me can exist. I hope all of this will be taken into consideration so arthritis victims can get some help.

JEANNE SNELL  
St. Louis, Missouri

October 28, 1975

I am sixty years old and have suffered the torments of rheumatoid arthritis for twenty-five of them.

In 1956 when the first symptom made itself known it was diagnosed as rheumatoid arthritis after I had undergone a complete physical at one of the leading hospitals. My instructions were to take two aspirins every four hours around the clock.

As time went on the pain and nervous discomfort prompted me to try about every quack remedy I ever heard about and some of them were pretty terrible.

In 1961 I was working and was on my feet quite a lot, the pain and swelling was so bad I was taking strong doses of cortisone in tablet form and shots under my kneecaps so I could stand.

In August, 1961, I had a complete breakdown caused from the side effects of the cortisone treatment. My blood count went down to 9.6. I was hospitalized for twenty-nine days and when I was released I had lost thirty-five pounds and was unable to navigate under my own power. It was indicated I would be a semi-invalid or be in a wheelchair the rest of my life.

As time passed circumstances altered that. I was forced to summon all my strength and willpower to fight this dilemma.

Through the years that followed the loving family care, a selfish domineering husband, and the concern of my doctor helped me to fight it with all my heart.

In 1973 I had a complete foot reconstruction on both of my feet which made a terrific difference. My hands are deformed and ugly but they are limber and there is very little pain.

I hold a full-time job, drive a car, do all my own housework, laundry, shopping and etc. I take minimum doses of Prednisone daily and a minimum gold shot once a month. My blood pressure and heart is checked once a month and my blood count is taken twice a year.

I feel my worst when I am unhappy or depressed or when the wind blows for long periods of time.

There are a lot of funny and sad stories to tell when I reflect back over my life with this disease, but I feel very fortunate I have come as far as I have.

MRS. FLOYD TRASTER  
Hopkins, Missouri

October 25, 1975

I am 73 years old. Rheumatoid struck all at once in both knees; also have osteoarthritis in one of my knees. In a short time went to my family doctor, he diagnosed it as such. Entered the hospital in Maryville, Mo., Sept. 16 to Aug 25, 1963.

In Columbia, Mo., from Aug. 25 to Sept. 3rd 1964. Which was the last time I was able to walk. I had a specialist who didn't seem to know too much about the ailment. Was sent home, told to exercise, take pain pills, hot water baths which I faithfully carried out. They did say an infection which I had from bad tonsils could have been the forerunner. They were taken out May 19, 1920.



Had a very bad case of calcium deficiency in 1962. After being in a wheelchair 9 years and 2 days an operation was performed on both knees. They are new, work fine, still have arthritis in them. After being in the hospital 87 days, recovering and therapy was sent home on crutches. Walk now with a cane, which I will always have to do. My ankles are bad, wrists stiff, fingers out of shape. In my shoulders, back of head and neck. Elbows--one is stiff cannot straighten. That arm is 2 or 3 inches shorter than the other. I've suffered real bad all last winter and this summer. The pain pills don't seem to do much good. I've taken many different kinds over the years among those are Taurin, Darvon, am now on Tylenol 3. They don't seem to do much good. I'm allergic to Anacin, aspirin, and Bufferin. Never taken cortisone in any form.

There are many things I cannot do, days I'm not able to do anything. The family has coped very well, took time and some doing, otherwise I would never have been able to make it. I owe very much to them. The many trips to the doctor which never did seem to do any good.

I've had many different kinds of sickness, none so terrifying, wondering when another limb will refuse to work.

Would like to see in my lifetime a preventive cure, or at least something to make the pain more bearable. I certainly hope you get many letters, have several cases in this small town. Some young people, who are in a bad shape.

Hope they are able to write. I can't think of anything that needs more research, that takes money.

MARCINE WATSON  
Barnard, Missouri

I am Mrs. Traster's daughter. The surgery my mother had on both knees in 1972 was in her case very successful. She had not taken a step in nine years and we had given up hope of her ever walking again. She had a very skilled orthopedist and she had a lot of determination, and faith that she would walk again. This type of surgery is wonderful; but it is being done very rarely on people under fifty years of age. At least that is the situation in this area. I have three friends in their early forties who have been stricken with this dread disease and there seems to be little that can be done about it.

I do hope you hear from many arthritis victims and that very soon there will be money made available to conquer this crippler.

GRACE COUNTS  
Kansas City, Missouri

October 29, 1975

I am submitting this written statement in support of the need of funds to implement the provisions of the National Arthritis Act.

I discovered I had arthritis approximately ten years ago. After several visits to the doctor, I was given that diagnosis about a week after X-rays. I believe I have been receiving the care and education that is available. However, to this date, I still stand and walk in a stooped position with the aid of canes, and suffer pain periodically. As a result, I am hampered in performing many daily duties and activities that others partake in.

My family and I have become resigned to the fact that nothing else could be done about my disease. Therefore, we are very pleased to know that there is the probability of further research through this act.

I sincerely hope that funds will be provided for programs to enhance medical care and to help wipe out this disease. 3227

JOHN L. FERGUSON, M.D.  
Springfield, Missouri

October 28, 1975

I am writing in regard to the hearings which your Commission is conducting across the nation as to what course the National Arthritis Act should take. Because of previously made practice commitments, I will be unable to attend the meeting to be held in St. Louis, but would like to have my feelings made a part of those proceedings.

I strongly concur with the Commission's intent to create more research traineeships in this field, because only as causes are discovered and better treatments are made available can the practicing rheumatologist do a better job. However, I would like for the Commission not to forget an immediate and critical need, that being to supply the American public with more physicians who are adequately trained in the field of arthritis and rheumatic diseases. One sees the figure frequently used that there are over 20,000,000 people who have some type of rheumatic disease that requires medical care. This figure does not surprise me, but a fact which is just as important is that there is probably an equally large number of people who think they have some type of rheumatic disease but do not. Contrary to all of the publicity which is being given regarding the need to increase the number of family physicians at this time, my experience is that with the increasing sophistication and knowledge of the American public, once a person suspects or is told that he has a rheumatic disease, he immediately wants to see a specialist, i.e., a rheumatologist. It goes without saying that the present supply simply is unable to meet the demand.

I realize that with limited resources priorities will have to be set. My intent in writing you is simply to voice a plea from a practicing rheumatologist's standpoint--PLEASE SEND HELP!

I appreciate the time and effort your Commission is devoting to the implementation of this law and am confident that your decisions will be the correct ones.

SARA MINCHEW  
Brandon, Mississippi

October 29, 1975

I, Sara Minchew, age 37, have been a victim of arthritis since the age of 16. In 1962 I had my first surgery on my left hand at the University Hospital in Jackson, Miss. Since that time I have had ten surgeries through the arthritis clinic in Jackson, Miss. Through this help of the arthritis clinic I was able to continue working and taking care of myself until two years ago. The last two years I have become disabled because of my right knee and my right hand and am totally dependent on my sister to care for me and she has a large family of her own. If I can continue receiving help from the arthritis clinic, surgery can be performed on my right knee and right hand so that I might be able to support myself again.

For two years I was not eligible for Medicare and I received no other government help. Because Medicare and Medicaid does not cover my pain medicine, my drug bill is tremendous.

I would like to see more money appropriated for research for finding a cure for those that are already crippled with arthritis and those that will become crippled with it.

Through the help of the arthritis clinic and God I will walk again.

HAZEL NELSON  
Kansas City, Missouri

October 29, 1975

As I am a victim of arthritis, I am interested in any meetings or hearings pertaining to it.

In 1956 I was told by my doctor that I was getting arthritis and he sent me to Dr. Stewart Gillmor, then director of the Arthritis Foundation. I was told I had rheumatoid arthritis and the treatment would be lengthy and costly, but perhaps I could get help through the foundation. And have continued to off and on since. Have just returned after being a patient at a private physician.

One reason for returning to the foundation and perhaps one of the most important is that I get quick and better results from my medications. Also I have faith in the sincere people who are connected with the Foundation. They are concerned dedicated people who care.

Although I have struggled with rheumatoid arthritis and have a few scars such as cervical spine and foot scars, I feel that the early diagnosis and treatment that I received from the Arthritis Foundation made it possible for me to work part-time, as a sales person until my retirement.

I think with more research and training programs expedited that perhaps in near future a cure or near cure can be found for the sufferers of a painful, crippling, dreadful disease: arthritis.



MILTON H. RUDI  
Kansas City, Missouri

October 29, 1975

I am submitting this statement to you in advance of the meeting being held in St. Louis on November 11. I sincerely wish I could attend, but I must remain here in Kansas City to direct the premiere of a mass which I have written. However, please accept this statement as a record of my experiences and thoughts about the treatment of arthritis and its victims.

I am a professional musician and music store manager, and my livelihood depends upon my ability to perform and meet the general public. I have arthritis.

I was only 26 years old and married for five months when the initial symptoms presented themselves. The migrating joint pains and general fatigue were finally diagnosed at a local clinic, and I was told that I would just have to learn to live with the discomfort. Armed with a neck brace and some pills, I spent the first six months gradually slipping in my ability to function with the disease. I tried hard not to limp as I walked in public. I couldn't shake hands anymore. On Sunday morning it was a real effort to make it through the service. At this point I thought that my working career was over and that my wife would have to support us for the rest of our years together.

Since I hail from a family of doctors, one would think I should have received the best of care and advice regarding my disease. My father told me my condition was psychosomatic. My uncle gave me steroid pills that I was taking every day--a regimen that can be dangerous over a period of time. And, of course, I received a multitude of "wish you wells" and prayers, none of which really helped me over the long run. I progressed from the general soreness to acutely involved and inflamed joints.

I finally learned of the Arthritis Foundation when I asked a doctor in our church where I could go for competent treatment, and I was extremely lucky to be admitted as the clinic was filled and I did not qualify as an indigent. Since that time the treatment and course of my disease has been managed to the point where I am now able to function as a normal person. And while I understand these symptoms can come and go, I know it was due to the treatment and care I received at the clinic.

Treatment and care is an ongoing process for the arthritic. It involves frequent visits to the doctor for reevaluation of the disease process, changes in treatment strategy, many physical exams, blood tests and X-rays, education for adjusting one's lifestyle, and exposing quackery in treatment.

The long term management of this disease is seldom profitable for a practicing physician. Patient visits are usually short, treatment is not dramatic, and many times the best result that can be achieved is a holding action against the progress of the disease. Perhaps this is why there is such a shortage of qualified rheumatologists available to the arthritic.

At the moment, the physical and psychological trauma has subsided with the ebbing activity of my disease. How long this will continue, I don't know, but the possibility of it returning is great. I feel deeply for all those whose crippling and pain make day-to-day living a sheer effort and whose only desire is to find relief from it all. I am lucky and am willing to do all that I can to help in the fight against America's number one crippling disease. Because of the numbers of people with arthritis and its accompanying economic loss to this country, I feel it is in the national interest to find the cause and cure for this disease, and I urge the National Arthritis Commission to do everything in its power to make that a reality.

WAYNE M. HESSER  
Fairchild AFB, Washington

October 28, 1975

If there is anything I can say about my mother's lifestyle it is that it has always been active. While taking pride in her home its walls have never been her boundaries. Her lifestyle has included teaching from sixth grade through high school and community work which has taken her throughout the state. Her recreations have been similarly enthusiastic. Ours was always an outdoor family. We have been campers, swimmers, hikers, and travelers from my earliest memory. It is not in her nature to stand and watch. Her life has been that of a doer, a teacher, a helper, a worker, and a whole hearted enjoyer of life. How cruel that such a person should be struck with rheumatoid arthritis.

How can a person react to such a blow? In my mother's case the reaction was denial, not a self-pitying denial of the reality of what had happened or a weakling's simpering denial of the ability to go on, but the defiance of a strong and vibrant person in the face of hardship. She chose to resist, to stand and fight to the best of her ability. Through self-discipline and persistence she has held her disease at bay and limited its effects as much as present knowledge of its treatment will permit. The exercise is hard and painful; the professional care is expensive and often even more painful. She has borne it all with patience and courage even with the knowledge that victory can at best be incomplete. Lost ground can never be recovered.

For those of us who can only watch and wait, it is also a painful experience. I work as an Air Force aircrewman, and my wife is a student nurse. We are both believers in positive action. We have both been taught the necessity to do something in time of crisis. What can we do here? What can we do but watch the slow deterioration wrought by this crippling disease? What can we do but watch her fight this uphill battle where all the odds are stacked against her? Helplessness is a terrible feeling. It's horrible to watch a loved one suffer and not be able to give aid or assistance. Perhaps the only thing worse than such helplessness is hopelessness. We have not yet lost hope. We believe that research can provide new answers, new methods of treatment, and maybe someday even a cure. People like my mother are making a truly heroic effort. They deserve help and support. They deserve to be able to live the full and productive lives that their Creator intended. They deserve hope.

AUSTIN R. TINSLEY, M.D.  
Poplar Bluff, Missouri

October 31, 1975

I am a family practitioner in Poplar Bluff, Missouri, a town of approximately 17,000 with a much larger patient clientele. This southeast Missouri area, of which Poplar Bluff, Sikeston, and Cape Girardeau are the largest cities, serves an eighteen-county area. There are no rheumatologists in this area which has greater than 23,000 afflicted with arthritis. Similarly, there is a lack of educational and assistive facilities in this rural area. The area is served by the Eastern Missouri Chapter of the Arthritis Foundation but the funds to reach the indigent in this area are not available.

I have trained under Dr. Gordon Sharp at the University of Missouri in Columbia, and have been involved with him and physicians interested in arthritis in trying to serve the people in the southeast Missouri region. We have compiled a preliminary proposal for a branch office of the Arthritis Foundation in this eighteen-county area and I am enclosing copies of the goals, objectives, and statistics on the area with which I am most concerned. There is an obvious need in all of eastern Missouri, but the need is blatantly obvious in the southeast Missouri region.

I hope this will help shed some light on the grave situation in this area and hope that the National Arthritis Act will be implemented in the near future.



PRELIMINARY PROPOSAL

for a  
Branch Office  
of the  
Arthritis Foundation

Submitted by:

Austin Tinsley, M.D.  
Family Practitioner  
Poplar Bluff, Mo.

and

Marilyn Merrell  
Regional Health Educator  
Ozark Foothills Regional Health Agency  
1618 North Main  
Poplar Bluff, Mo.

### GOALS

To give arthritic patients an understanding of the illness.

To provide the necessary education, concern, medical services, and devices to aid in the adjustment and improvement of their condition.

To provide doctors with the necessary updated medical knowledge in caring for arthritic patients.

To provide doctors with a greater awareness of available services and medication.

### THE NEED

In the eighteen counties consisting of 10,489 square miles and 361,540 population as of the 1970 census, there are approximately 23,423 arthritic patients.

Those 23,423 arthritic patients are currently limited in their service by the Arthritis Foundation.

Arthritis causes and cures are still unknown. It is known that arthritis is one of the most painful crippling diseases affecting Americans every day, but a cure has not yet been found. The eighteen-county area offers no available aid to these individuals who cannot afford extensive care. The goals clearly point out that the purpose of an Arthritis association extension in this eighteen-country rural area will help all arthritis patients, but geared to those medically indigent patients who cannot afford care.

STATISTICS ON AREA TO BE SERVED  
(Based on 1970 statistics)

	Square Miles	Polulation
Bollinger	621	8,820
Butler	715	33,529
Cape Girardeau	574	49,350
Carter	506	3,878
Dunklin	543	33,742
Iron	554	9,529
Madison	496	8,641
Mississippi	415	16,647
New Madrid	679	23,420
Pemiscot	493	26,373
Perry	471	14,393
Reynolds	817	6,106
Ripley	639	9,803
St. Francois	457	36,875
Ste. Genevieve	499	12,867
Scott	421	33,250
Stoddard	823	25,771
Wayne	766	8,546
Totals	10,489 sq. miles	361,540 pop.

Age	Population	
0 - 44	232,058	- *15 arthritis/1000 people
45 - 64	80,355	- *154 arthritics per 1000 people
64 -	49,126	- *154 arthritics per 1000 people

=23,423 arthritic  
patients

\* Based on statistics from the Primer on the Rheumatic Diseases, page 17. Reprinted from The Journal of the American Medical Association, April 30, 1973, Volume 224, Number 5.



OBJECTIVES

- A. Establish advisory board and provide necessary facilities.
- B. Patient needs:
  - 1. To provide patient education on the arthritic condition.
  - 2. To provide medical services in specialized care, from doctors, physical therapists, and arthritis centers whenever necessary.
  - 3. To provide assistive devices such as walkers, canes, and exercise equipment on a temporary basis.
  - 4. To aid in providing medication on a partial pay basis for medically indigent patients.
  - 5. To provide transportation to medical facilities.
- C. Education of medical personnel within the existing eighteen-county community.
  - 1. To provide doctors with literature both for patient education and medical information.
  - 2. To inform doctors of existing services both from the Arthritis Foundation and medical arthritis centers.

HAROLD R. WARD  
Indianapolis, Indiana

October 17, 1975

Throughout the last four years I have been traveling across Indiana on behalf of the Arthritis Foundation, Indiana Chapter. It has been appalling to me to find that there are only fifteen rheumatologists in the State. Three of the fifteen are primarily research specialists for pharmaceutical companies. Three are primarily orthopedics, two are primarily internal medicine, and seven are the arthritis specialists available for differential diagnosis and treatment. Two of the seven are now taking patients only on referral from another physician. You, therefore, can see the problem of the estimated 437,926 people in Indiana with arthritis bad enough to need to see a physician who knows the latest in diagnosis and treatment of arthritis.

Until a recent announcement indicating there will be a department of rheumatology at Indiana University Medical School starting about November 1, 1975, there was little exposure of students to the arthritic problem. Now that this is apparently being corrected we would hope the National Arthritis Act would make it possible for arthritis centers to be established across the State so both student and patient could learn the better ways to handle this devastating disease.

For those who cannot afford the specialists we have only one clinic in the State now staffed by a rheumatologist that charges according to one's ability to pay. This is the clinic located at Wishard Memorial Hospital in Indianapolis. This is fine for Indianapolis and vicinity, but doesn't help people who live in outlying parts of the State.

We look forward with confidence that the National Arthritis Act will be fully funded and states like Indiana, who are not adequately served by rheumatologists or clinics, will be better able to take care of the people suffering with the nation's number one crippling disease.

JOE EISBERG, R. PH.  
Kansas City, Missouri

October 27, 1975

Approximately eight years ago Dr. Sisk talked to our annual board meeting and explained that our government, by whom he was then employed was looking for a model clinic in one of the established arthritic chapters. We, here in greater Kansas City, have been working toward that goal for eighteen years before that talk and eight years after. Dr. Gillmor was the founder of our chapter back in 1949. He was solely responsible for a \$300,000 gift which one of his patients wanted to leave him personally. However he directed the gift to our chapter. Many prominent Kansas Citians served on our board, among them A. B. Eisenhower, Jack Henry and Mr. Sosland. After a few years the gift grew larger and we built the three story building in which our present clinic is located. Under Dr. Gillmor's guidance we established what we felt was one of the finest physical therapy units in the country, with the very latest in equipment, including a tank where a patient could be hoisted into it, could stand erect from a wheelchair to be able to be completely covered to his neck.

It was Dr. Gillmor's desire to establish a chair of rheumatology, it is vivid in my memory, for about ten years ago I attended a regional meeting in Dallas, when our president was unable to attend, when I returned I found that Dr. Gillmor had died. Some time later Eric Williamson, a patient of his, who worked very closely with him, was instrumental in giving several hundred thousand dollars of our capital along with most of our equipment to the Rehabilitation Institute. Since that time our chapter has had a doctor in charge, patients were seen and a lot of the other work was farmed out.

Three years ago Dr. John D. Arnold opened a private practice on our east side, where I have been in business for almost thirty-two years. He had been the medical director of the Harry S. Truman Medical Research Laboratory. Actually he was the director. Since that beginning in a building that was built by Dr. Harry Underwood that housed another M.D. and two dentists, Dr. Arnold bought and remodeled a building across the street, which now houses the Quincy Laboratory, built a two story and a three story building, which houses his Quincy Research Laboratory and the two story building will accommodate forty paid volunteers used in controlled studies for twenty pharmaceutical houses.

A year ago Arthur Burger, administrator for the center asked me about obtaining some hot arthritics for a study. I brought Gordon Waller, our executive director, for a thirty-minute tour of the complex. A few months later Dr. Arnold was spending Wednesday, his day off, at our clinic seeing patients. Trying to capsule the progress we have made, I heard this statement from Mr. Waller. I have learned more about the operation of a clinic from Dr. Arnold in the past few months, than I had learned in the previous eight years.

At our executive board meeting about six weeks ago we voted to buy G.E. X-ray, slit lamp and screening equipment for hearing and to lease a Norland Cameron bone mineral analyzer made by G.E. for measuring bone density. This is at Dr. Arnold's suggestion and will be under his direction until December 31, 1976. Two of our board members, John Kroh and Kenneth Smith are donating \$10,000 each toward the purchase and construction of three rooms to house this equipment and for installation, which will hopefully begin in two weeks so that it will be operational by the first of the year.

In addition to our use of the Norland Cameron equipment in testing for our patients, we will be doing these tests for a large number of doctors who are doing work in osteoporosis. At present there is not an operational piece of equipment there. There are three in St. Louis, one under the operation of Dr. Avioli. I will enclose explanations both of St. Louis and where Dr. Arnold was operating one here for over a year. About six months by Dr. Dukstein and for the past few months by no one. There are now a large number of patients waiting.

We feel that the direction in which our clinic is headed will be by far the finest in the country and should be duplicated all over the country. How far our money will go is questionable. But at least we can set up a pilot program. Our nursing staff is being trained by Dr. Godfrey to interview patients that will allow doctor to see six times as many patients. What I am trying to say is that with whatever financial aid you might give you can obtain the biggest bargain in medical care for the arthritic with the least amount of dollars spent. We have practically no administrative charge where present grants that have been allowed soak up almost half in that fashion.

Reading what I have written at this point sounds like riding a pink cloud, but under Dr. Arnold's direction I feel that it will come true. He came to Kansas City when he was forty years old from Chicago where he was assistant professor of medicine at the University of Chicago, was professor of medicine at the University of Missouri at Kansas City and Director of the Truman Laboratory funded by the Army. When it was phased out Dr. Arnold moved to the east side and his major interest is the operation of the Quincy Research Center. Those of you who attend the meeting in St. Louis could very simply come to Kansas City and see the miracle he has wrought in the last three years. It was televised on the CBS morning news program last month, showing how he uses paid volunteers rather than inmates of penitentiaries. Again putting it in simple words he is a doer not just a dreamer. Repeating myself, for those of you that came from the west it will be a simple stopover. A telephone call will



bring you roundtrip transportation from and to the airport. As we in Missouri say it, seeing is believing.

ROBERT M. WHITE II  
Mexico, Missouri

October 18, 1975

My town, Mexico, Missouri, population 11,804, is pioneering a strenuous effort to see if we can't help our friends and neighbors, not only in the town but in the surrounding area, to get better and more meaningful treatment for their arthritis.

As all of us know, every family has someone in it with arthritis problems, and some are more serious than others

We have started a planned effort which includes helpful steps such as:

One, getting coordination from the Arthritis Center at the University of Missouri School of Medicine to send speakers over to talk to our doctors and to our nurses and other hospital personnel about how arthritis can be better recognized and treated.

Two, a local foundation put up some money for a countrywide survey which clearly discloses not only the interest so many people have in doing something about arthritis but the need for still more to be done about it.

Three, now we have set up a nonprofit corporation and believe we can get a program going in our county hospital which will lead to increasingly improved recognition of arthritis and increasingly better treatment of cases of arthritis.

Four, we hope to accomplish still other steps which will lead to fewer people being handicapped by arthritis in our area.

No, we do not have any special incident of arthritis; or at least we don't think so. But we do know from medical reports that arthritis is our country's "number one crippling disease" and we believe it must be the same for our county and town.

So, again, we as citizens are doing our best to do something about arthritis recognition and treatment here. Any improved national effort for still better research and still better cooperation down here at the local level should certainly help a lot of people. Because, if what we are doing here can help us, then a similar idea in other towns and even in cities could help an awful lot of other people.

St. Louis, Missouri

November 11, 1975

R. T SCHULTZ, M.D.  
Oklahoma city, Oklahoma

November 4, 1975

With regards to the development of a long range arthritis plan for this country, my major concern is that there be continued development of centers throughout the country which have as their major purpose, research and development and training of physicians in the study and treatment of the rheumatic diseases. Even though there has been considerable progress since World War II in the management of patients with rheumatic diseases, our over-all efforts to date still remain unsatisfactory. If arthritis research and training centers are not maintained, further progress in the understanding and treatment of the major rheumatic disease will be exceedingly slow. If the idea of arthritis research and training centers is dropped, then the burden of maintaining skills in rheumatology will fall on the shoulders of physicians in the clinical practice of rheumatology. No doubt this will result in maintenance of our present skills in treatment of the rheumatic diseases but this would only then maintain what is at present an unsatisfactory state of affairs. I would strongly advocate that some provision be made to maintain and develop arthritis research and training centers. Of course, this would have to be done within the limitations of funds that are available.

More can be done from the standpoint of professional and public education and no doubt better systems of data collections and recording are available. The crucial factor though in the implementation of these things is the development and maintenance of arthritis research and training centers.

AN ATTACK ON THE ARTHRITIS PROBLEM  
in the  
METROPOLITAN CHICAGO-MIDWEST REGION

FROM THE  
ILLINOIS CHAPTER, ARTHRITIS FOUNDATION  
CHICAGO, ILLINOIS



CONTENTS

Preface

- I. Scope of the Problem
- II. An Attack on the Arthritis Problem  
Metropolitan Chicago-Midwest Region
- III. Funding
- IV. Supplemental Information

PREFACE

The Illincis Chapter of the Arthritis Foundation was founded in Chicago in 1949 and is the sole voluntary health agency in the nineteen northern counties of Illinois dealing with arthritis, and coordinating the regional arthritis effort.

The Midwest Regional Arthritis Center, created in 1974, is a realistic regional program of the Illinois Chapter, and embraces every aspect of prevention, case-finding, treatment, education and rehabilitation. Its activities are under the direction of an advisory committee composed of physicians and allied health professionals from major rheumatology units, and community leaders from the Chicago area. The foundation and its Midwest Regional Arthritis Center Program have the endorsement of the Children's Memorial Hospital, La Rabida Children's Hospital, Loyola University Medical School, Michael Reese Hospital and Medical Center, Northwestern University Medical School, Rush-Presbyterian-St. Luke's Medical Center, and the University of Chicago, as well as all applicable professional societies and the local public and governmental agencies concerned with prevention, treatment and cure of arthritis.

The center program is not a building, but an administrative coordinating body, conceived by the board of the Illionis Chapter to meet an urgent regional need. One of its principal purposes is to help in the expansion and intensity of the foundation's efforts to provide vital information to all arthritic patients in this area, including those already in the crippling stages.

Many arthritis victims would find relief from pain and avoid crippling effects if they received early diagnosis and were given proper treatment. The educational program is directed to this group, and the mailing list for free literature is now over 56,000 people.

The foundation has an active board composed of business and financial executives. Dr. Peter Wolkonsky, president of the chapter, is the Medical Director for Standard Oil Company (Indiana), and is himself an internist and rheumatologist.

The Illincis Chapter is wholly dependent on private support and does not participate in the Crusade of Mercy or receive government aid. Requests have recently been made for the first time to foundations and corporations for support, and have met with moderate success. Adequate corporate support from companies with headquarters elsewhere is not promising, and many Chicago-based companies make their total welfare contribution to the Chicago Crusade of Mercy. These two situations make it very difficult for this foundation, dedicated to fighting a serious group of diseases, to raise funds of the magnitude needed to fulfill its objectives.

With this as an introduction, we respectfully refer you to the following pages and sincerely hope we will be included in an award. We would welcome the opportunity to answer any questions you may have or to discuss our programs in person.

Part I: The Scope of the Problem

There are 20 million people with arthritis living in the United States. It is estimated that 30,000 in the Chicago area alone have rheumatoid arthritis, and that 60 percent, or 600,000, have degenerative joint disease of varying degrees of severity. Forty percent of individuals afflicted with arthritis are not receiving optimal medical care, and 19 percent of those affected have never been given any medical attention. It is projected from present national figures that 1,200 children in Illinois under 16 have juvenile rheumatoid arthritis. Nationally, 250,000 children in the United States suffer from juvenile arthritis to such an extent that they require medical care.

With over 20 million Americans having arthritis of some type or degree, and with the proportion of the population in the over-55 group ever increasing, this problem can only worsen. The most disabling varieties, such as rheumatoid arthritis, typically occur during the productive period between ages 20 and 50. As a result, over 50 million working days are lost each year and the total cost to society in terms of medical costs, time lost from work, and rehabilitation, nursing, and all the other costs of dealing with this group of diseases, was over \$9.2 billion annually in 1972, and is certainly higher now.

The nature and chronicity of most of the rheumatic diseases pose a different problem; unlike patients with cardiovascular disease and cancer, who generally have illnesses which are potentially fatal, and are thus self-limiting patients with arthritis represent a long term burden for themselves, their families, and society, if not adequately managed from the earliest stages.

In addition, there are certain resource limitations in handling these problems on a regional basis: there are only about 20 rheumatologists in Illinois, with all but three based in the Chicago area; rehabilitation centers are woefully few; there is no "halfway" house for the care of the arthritic in Illinois; while schools for allied health professionals are scattered throughout the state, their training is minimal regarding certain aspects of the care of the rheumatic patient; some existing and major medical institutions still lack specialized staff for an active rheumatology program; and there is a maldistribution in the region of rheumatological talent, both as to the rural areas and in the ghettos of the city.



Part II: Attack on the Problem--Objectives

A more intense, coordinated effort, regional in scope, is needed:

- (1) To bring more patients into contact with quality specialized treatment.
- (2) To improve the effective medical management of this increased caseload.
- (3) To expand professional training and public and patient education, and the development of new clinical and personnel standards and facilities, including innovative home care and midway care methods.
- (4) To do so through a coordinated program, maximizing the cooperation and utilization of all the region's specialized medical, community leadership, and related public professional and private resources.

The Regional Arthritis Center

The center was created in 1974, and its fiscal and administrative agent is the Illinois Chapter of the Arthritis Foundation. The chapter is particularly well qualified to develop and administer this regional effort. Unlike any existing agency, and alone among voluntary health agencies, it already plans and coordinates the total regional effort in arthritis. The center was created with the assistance, agreement and participation of every existing medical school rheumatology unit in the region, as well as those professional, public, and government agencies sharing a concern with the varied aspects of these diseases. These organizations include:

Participating Institutions--Children's Memorial Hospital, La Rabida Children's Hospital, Lcyola University, Michael Reese Hospital and Medical Center, Northwestern University Medical School, Rush-Presbyterian-St. Luke's Medical Center, University of Chicago

Professional and Academic Organizations--American Academy of Pediatrics, American Physical Therapy Association, Chicago Orthopaedic Society, Chicago Rheumatism Society, Illinois Occupational Therapy Association.

Governmental, Third-Party, and Other Agencies--Blue Cross/Blue Shield of Illinois, City of Chicago Board of Health, Comprehensive Health Planning, Inc., Council for Community Services, Illinois Hospital Association, Transportation Center of Northwestern University, United States Department of Transportation

To implement the programs of the chapter and center, the medical institutions listed above have expert specialists, staffs, and facilities for the management of rheumatic diseases, and effective integration with professional and public agencies. This will provide an ideal arthritis

center. From a regional standpoint, four of the participating medical schools already maintain networks of closely affiliated community hospitals; these hospitals number some 20 at present, and this number and geographical spread will be increased as other participating institutions develop such networks.

Consistent with the chapter charter, the center's activities are under the control of an advisory board, composed of physicians and allied health professionals from the major rheumatology units, and of community and lay leaders and patients; these include individuals currently affiliated with the Illinois Chapter, as well as others.

### Part III: Funding

The Illinois Chapter of the Arthritis Foundation has operated on approximately \$225,000 annually. To expand its current programs, and to finance the Regional center, the chapter will need \$403,000 in 1975, and \$419,500 in 1976.

The chapter is tax exempt. It is virtually totally dependent on grants and bequests from private sources such as individuals, foundations, associations, and corporations. Therefore, your support is crucial.

### Your Contribution

In view of the universality of this group of diseases, the tremendous financial and human price they exact yearly, and the present woefully inadequate capability for dealing with them, we earnestly solicit your favorable consideration for a major grant.

### Accountability

That a grant will be wisely and constructively used is assured, not only by the caliber of the medical institutions and the professional groups listed earlier, the lay advisory groups responsible for administration of the chapter and the center, but also by the provision in our administrative procedures for a required annual evaluation of our goal achievement and performance. For example, we and participating institutions have agreed on quantified goals wherever possible, so that performance can be assessed in quantitative as well as purely qualitative terms.

### Evaluation

Implicit in the Illinois Chapter's planning is provision for on-going evaluation of its programs, with the view of assessing program effectiveness in meeting our objectives, and the further view of doing so with the most efficient and productive use of our financial and human resources.

Short term, the evaluation process will be based largely on specified quantified goals and timetables, and accordingly will be essentially internal.

This internal review will make use of the unique management skills of the advisory groups, who will further be looked to for assistance in developing a management information system to provide essential long term evaluation and review procedures and techniques. Development of such a system will ensure the proper obtaining and review of data necessary to our operations objectives, which, however implemented, seek ultimately greater benefits for greater numbers of patients. Thus, it is planned to develop the review mechanism in such a way as to permit application of modern management techniques to such diverse center activities as clinic care, nurse-practitioner performance, midway and outreach programs, development of standards and protocols, etc.--in brief, for objective assessment of the total chapter and center activity.

It is expected also to develop an assessment procedure involving public and professional groups apart from those already represented in the organization. It is hoped that, much as with independent evaluation of research proposals, professionals from outside the Illinois region will pay a key role in evaluation of our performance.

At the end of each year, an evaluation document will be prepared, reviewing not only the specifics covered in the present programs but also directed to the handling of such problems as may have arisen, new techniques of organization and administration which may have been developed, and distinctive features of our program (such as our advisory groups) which may have been significant in the program's functioning.

Should you have questions, or require more detailed information on any aspect of this proposal, please let us know. The contribution may be sent to the Illinois Chapter of the Arthritis Foundation at 159 North Dearborn Street, Chicago, Illinois 60601.

#### Part IV: Supplemental Information

##### Rheumatology Resource Units Utilization

- I. The Chicago area has expert staff and facilities for the management rheumatic diseases, comprising the Children's Memorial Hospital, La Rabida Children's Hospital, Loyola University, Michael Reese Hospital and Medical Center, Northwestern University Medical School, Rush-Presbyterian-St. Luke's Medical Center, and the University of Chicago.

Each of these units serves a geographically discrete population, so that their effective integration has the potential to provide an ideal regional arthritis center. Of these units, the Children's Memorial Hospital and La Rabida represent two of only a handful of pediatric training units for rheumatology in the country.

Four of the participating medical schools maintain networks of closely affiliated community hospitals used for student and



house-staff education and patient referral. There are 20 of these hospitals at present.

The Illincis Chapter currently contributes to the support of twelve rheumatology clinics, some of which are located in participating rheumatology units, and others in community hospitals.

Metropolitan Chicago is served by four Veterans' Administration hospitals. Two of these have close ties with rheumatology training units; the one at Hines, Illinois, with Loyola University, and the other, the Veterans' Administration Research Hospital, with Northwestern University Medical Center. A third V.A. hospital, located in the medical center area of the University of Illinois, Cook County Hospital, and Rush-Presbyterian-St. Luke's, has a physician on its staff with a strong interest in rheumatology. The fourth hospital is a facility for chronic illness at Downey, Illinois, that is without an organized rheumatology program at present.

Thus, strong ties bind two V.A. hospitals to their medical center rheumatology units, with the option for the third to do likewise when its affiliated center, the University of Illinois, activates such a unit.

- II. Two main kinds of rheumatology units exist at the participating institutions. All provide full range patient care, some are equipped and staffed to train rheumatologists and related allied health professionals, while others are not.

Training units include those at Children's Memorial and La Rabida, Loyola, Northwestern, and the University of Chicago. Service rheumatology units, without fellowship training programs at present but with the full capacity to develop such programs, include the Rush-Presbyterian-St. Luke's Medical Center and Michael Reese Medical Center. Rush-Presbyterian-St. Luke's program has already been funded in an amount exceeding \$1 million for a chair in rheumatology.

- III. These Units are developing programs including:

- A. Expansion of their own and affiliated hospital patient loads by at least 10 percent in the first year, to accommodate the expected increase in referrals engendered by public education programs and the increased public awareness of the availability of such centers.

It is recognized that even this increased patient load can deal with only a small portion of those in need, and that personnel and physical resources do not now exist to handle all arthritics not now receiving care in the region.

Accordingly, an important part of the regional center's program will be to measure needs, and to develop methods to

handle a much increased patient load, including development of new resources and community networks of hospitals.

- B. Development of new specialized rheumatology units by at least three of the participating institutions. La Rabida Children's Hospital has for some years maintained a specialized rheumatology unit with designated beds, specialized nursing care, etc., and the University of Chicago has established such a unit for adults. It is the plan for at least three of the other participating institutions to seek development of similar units for inpatient care.
- C. Establishment of at least six arthritis clinics in outlying network hospitals, by both training and service rheumatology units.
- D. Region-wide provision of expertise in all areas requiring highly specialized diagnostic or therapeutic procedures. Among the participating units there are presently capabilities for the skilled performance of virtually every sophisticated or research-level procedure, and these resources will be made known to, and shared as needed with physicians and hospitals throughout the region.
- E. Expansion or establishment of training programs for up to 24 practicing physicians in the community who wish to take part, at their own expense, in a continuing education program, as well as for house staff physicians.

In such programs, openings will be made available for community physicians to spend a specific period of time in all arthritis units, where the training will be clinically intensive and will include hospital rounds and other appropriate learning experiences.

Resident level house-staff from hospitals without a formal rheumatology program will be offered positions for short term rotations in established rheumatology programs. No stipend will be provided.

#### Regional Arthritis Center Resource Utilization

The center will implement throughout its region the basic policy objectives stated initially by:

- I. Coordination of patient entry into the profession resources described above, and expansion of existing referral-center activities of the Illinois Chapter for patients seeking a rheumatologist and for community physicians with problem patients.
- II. Keeping an up-to-date file on available resources, such as medical and auxiliary staff, designated beds, special laboratory

facilities, and areas of particular expertise in the individual hospital units making up the Regional Arthritis Center.

- III. Development of a region-wide registry of arthritis patients, with their diagnosis, drugs, drug idiosyncrasies, etc., will be investigated. Data suitably coded to prevent patient identification would be made available to physicians and other interested parties throughout the region, and would be obtained by means of specialized forms, etc.
- IV. Development of statistical information necessary for the long term planning and operation of a self-sustaining program. In this respect, records will be kept of all referrals, units to which referrals were sent, areas lacking referral resources, and final assessments.
- V. The projects referred to in II-IV above are contingency items. If collection of the data described proves feasible, and analysis of the data allows for meaningful decision making, the programs will be continued at whatever level is deemed appropriate in meeting the center's needs.

Acquiring such a comprehensive data base, and easy access to it, would permit gauging the strengths and deficiencies of the program, documenting patients lost to follow-up, improving the continuity of care should the patient move to an area served by a different unit, and facilitating implementation of the center's innovative programs in such things as "midway care," and transportation and facility access, described below.

- VI. Development, promulgation, and establishment of regionwide protocols for diagnostic and therapeutic approaches to rheumatic diseases. It is essential not only to develop professional standards of rheumatologic practice, but to define formally for the non-rheumatologist, the public, the patient, and official agencies such as regional PSRO's, exactly what does or should happen under such standards to a patient with one of the rheumatic diseases as he enters the health care system.

Adequate professional standards are best defined as those standards of patient care generally practiced at a properly staffed arthritis clinic. The American Rheumatism Association has published a report on the proper composition of an arthritis clinic; and, consistent with their recommendations, the clinics presently supported by the Illinois Chapter have the following attributes:

- A. They are headed by someone knowledgeable in arthritis; this generally implies specific training or long experience or both.
- B. Necessary support facilities are present. These include adequate clinical laboratories and X-ray facilities, easy access to qualified physical therapy and occupational



therapy units, and ready consultation with skilled orthopedists and specialists in rehabilitation.

- C. They are either part of, or closely linked with a medical school with an arthritis unit.

Proper care for arthritic patients can only be achieved when at least attributes A and B above, obtain. Moreover, it is important to demonstrate that arthritis clinics based on such standards can do an efficient job in the quality care of patients with arthritis, so that referral to such centers will be stimulated.

Accordingly, the center will formulate specific protocols for the individual rheumatic diseases based on such considerations, and will offer them to all physicians in the region, as well as to interested government, third party payers, and professional organizations, as standards for their decisions regarding patient referral and handling. The center itself will also under these protocols, actively monitor the performance of the arthritis clinics that it now supports and the six new clinics it will sponsor in its first year.

- VII. Mobilization of volunteer teaching resources for patients and families will be undertaken. At present, little or nothing is being done in the region to use volunteers in a local environment as key components of such programs.

For example, retired or employed volunteers with various interests and skills are drawn from various trades, schools, industry, and business, have been used to teach and demonstrate how disabled arthritics can care for themselves in their homes and on jobs. While in some hospital environments such instruction may be easily available from occupational and physical therapists, many or most patients do not enter or remain in such environments.

The center visualizes development of a regional network of "public" classes for outpatient arthritis victims and their family members, such classes to be held in volunteered available local space (e.g., hospitals, schools, offices). Instructors would be those having special skills (e.g., carpentry, typing, sewing, cooking) and would themselves first be instructed (by the region's participating professional personnel) in the specialized modalities of occupational and physical therapy, such as joint preservation techniques and devices. Volunteers would have an on-going reporting relationship to their unit's personnel, but coordination and allocation of their teaching time would be handled by the regional center.

- VIII. Development of a nurse-practitioner (NP) training program. At present, there is a program in Chicago in the field of rheumatology, initiated and financed by the arthritis center. In

those teaching hospitals in the greater Chicago area which are developing nurse-practitioner programs, to date two have produced nurse-practitioners in rheumatology.

The center proposes to support continuing development of such efforts so that the shortage of qualified nurse-practitioners can alleviate the shortage of qualified rheumatologists.

- IX. Development of midway care programs, using nurse-practitioners and utilizing where possible existing community resources such as, for example, nursing homes. A survey will be made of existing nursing homes to determine the extent and level of specialized services currently available to the arthritic requiring such care. An attempt will be made to cooperate with those nursing homes expressing an interest in providing expanded care, with the view of designating such homes as particularly suitable for the needs of the arthritic patient.
- X. Inclusion of rheumatology in existing "network" liaison arrangements of the four university units with twenty neighboring community hospitals, in such forms as providing visiting rheumatology consultants and seminars.
- XI. Expansion of the present support level of twelve arthritic clinics currently being supported by the Illinois Chapter. All of these clinics give comprehensive care to arthritis patients regardless of source of referral.
- XII. Development of a public education program to carry to consumers and providers of medical care increased knowledge of what constitutes the quality care of patients with arthritis.

Programs will be developed to acquaint patients with the early signs of arthritis, motivate patients to seek qualified services, and develop more enlightened public attitudes towards arthritis.

- A. These approaches will include public forums, which have been sponsored throughout the region since 1966 by the Illinois Chapter, personal question and answer meetings, and specialized seminars such as the 1972 and 1975 one-day seminars on Arthritis in Industry, described more fully below. It is planned to conduct such seminars periodically, with the specific view of educating and enlisting support from this key element in the gainful employment of arthritis patients.
  - B. Media opportunities will be explored, including radio, commercial and public television, and possibly local closed-circuit or cable television, followed by objective assessment of the results of such efforts.
- XIII. Arthritis in Industry--In 1972 and 1975 the chapter sponsored symposia on Arthritis in Industry, the proceedings of which received significant press coverage, and were subsequently

published as a full issue of Industrial Medicine and Surgery. Medical directors and key executives of many of the major business and industrial concerns of Northern Illinois attending the symposia, in which all Chicago rheumatology units participated, as did other prominent professional, lay, and government leaders.

These seminars were the first of their kind for arthritis in the nation and were unique in the high level of participants, including members of the Advisory Board. The impact in acquainting business leaders and others with the problems of arthritis was significant and extended beyond the chapter's local area.

However, the problem of arthritis in industry remains unsolved. For example, one would expect large corporations to be leaders in hiring the arthritic, but most such corporations have generous sickness and disability plans, and are understandably reluctant to hire patients with known progressive diseases such as arthritis, not only because of concern over future work performance, but also because of the financial obligation the companies thus assume in the event of disability.

Since the goal of treatment and rehabilitation of the arthritic is restoration to productivity, and since productivity for pay requires a paying employer, i.e., "industry"--further exploration of this serious problem is clearly essential.

Because employers alone cannot bear the cost of continuing support of nonproductive or disabled employees, the problem is broadly society's. It may be that, as it does with other social programs, society should face up to its role in contributing to such support.

Accordingly the center proposed to conduct a survey of major industries in northern Illinois to ascertain variations in hiring, benefits, and retirement policies as they apply to individuals with arthritis.

XIV. Third party payers, and the various government agencies (local, State, and Federal) have been and will be made aware of the regional center program and will aid in support of applicable programs.

For example, in many programs patients with arthritis are in effect discriminated against because of the chronicity and nondramatic nature of their illness.

Accordingly, the center and its participating units will:

A. Offer the various PSRO organizations presently forming in our region the center's protocols for adequate care of patients with various form of arthritis.



- B. Offer expert counsel to the Illinois Department of Public Health and other agencies in the hope that reasonable rules can be established for patients with arthritis presently financed under such programs as Medicaid.

There seem to be no firm guidelines for the Hospital Admissions Selection Program (HASP) coordinators when dealing with arthritis patients, and many instances arise in which patients are denied hospital care they badly need.

- C. Direct links will be established with the State of Illinois Medichex program, a newly developed health screening, diagnostic, and treatment system for over half a million children from birth through 21 years of age.

- XV. Increasing the existing program of professional education, including support and coordination of specialist training within established rheumatology units, use of unit personnel in training and continuing education in local hospitals and communities, and center and unit sponsorship of seminars and symposia. The Illinois Chapter of the Arthritis Foundation currently sponsors or supports several such symposia and seminars, and the center will increase that support. Cooperating with the center, the Chicago Rheumatism Association, and rheumatology units will explore ways and means of increasing their teaching efforts to physicians, medical students, nurses, and allied health professionals.

It is hoped that this document may, in fact, be an initial guidebook to an innovative effort in regional delivery of improved health care.

ANITA MIKUS  
Florissant, Missouri

October 28, 1975

I am writing to you at this time to urge the appropriation of desperately needed funding for arthritis research. I am a 48-year-old victim of chronic rheumatoid arthritis. For the past 26 years, I have had a steady crippling process with the deterioration and deformity of the joints in the jaws, neck, shoulders, elbows, wrists, fingers, spine, hips, knees, ankles, feet, and toes. It is impossible to describe the excruciating pain associated with this disease because it not only affects the joints but also the muscles. Periodically it becomes more active in the throat muscles, making it difficult to swallow and when it flares up in the rib cage, every breath is labored. I wish I could say how many times I have prayed that I would just be able to retain my sanity until some of the pain would recede. How many arthritis sufferers lay awake night after night, month after month because the pain is so severe, and how many every morning cannot leave their bed or wheelchair?

This disease is not just felt by the victim--my children lived with the sight of their mother becoming worse year, after year and requiring surgery and hospital stays became a way of life. My husband works hard

and for the past 26 years a big percentage of his pay has gone for doctors, drugs, and surgery, with no end in sight. I have had surgery on both hips, both knees, both feet, both thumbs, and the right wrist in an effort to just keep moving.

Please, Mr. Wartofsky, give me, and the millions of arthritics like me, the chance to some day soon walk down the street holding my husband's hand instead of grasping my crutches.

KENNETH SMITH  
Kansas City, Missouri

October 28, 1975

It is so hopeful that we are on the road to doing something about arthritis instead of just talking about it. So many of us who have worked with Arthritis Foundation chapters for years are greatly encouraged that arthritis is now recognized for what it is, the greatest 'crippler' of all, the greatest expense to people and to industry because of its crippling effects.

The important thing is to fund the program adequately and to see that it is planned and executed with the expertise that will be required to do the job.

We wish you and the men who will be working with you success in dealing with this problem that too long has been just kicked around with the thought that you can't do anything about arthritis. That defeatist attitude never whipped any problem.

Kindest regards, from all of us who now feel hope for something that has been neglected for too many years.

DOROTHY BARNHART  
De Soto, Kansas

October 23, 1975

I am Dorothy Barnhart, age 35. I am married and have 2 children. I live at Box 336, De Soto, Kansas 66018. I got sick in 1971. I did not know what was wrong with me. I knew I hurt terribly and couldn't hardly get around. I had to be helped up when I sat down. So I started trying to get help from doctors. I went to 2 different doctors plus several days in the hospital trying to get help and relief. So after fooling around almost 1 year they told me there wasn't anything they could do to help me. So a friend told me about the clinic (Arthritis Foundation) and what they had done for her sister-in-law. I called the clinic and asked what I had to do to get into the clinic and they made an appointment for December 8, 1972. I went. They took the steps they needed to see what my diagnosis was. It was rheumatoid arthritis. They started me on shots and medication. I also had to wear splints on both hands. I also had to quit my job. I thought I was down forever. But thanks to Arthritis Foundation in K.C., Mo., I am up going again. I also went back to work and I am doing great. I still have to go to the clinic every 3 weeks. I think if I hadn't found the arthritis clinic I would be totally disabled today. I think if any place needs help financially the Arthritis Foundation does.

St. Louis, Missouri

November 11, 1975

If no one ever had the pain and suffering they have no idea what it is like. So please help.

JIM HAYES  
Maryville, Missouri

October 24, 1975

My name is Jim Hayes, and my wife is a victim of rheumatoid arthritis, and has been for nearly twelve years now. I have seen her go through pain and misery day after day and have to stand helplessly by and do nothing, only comfort and help in whatever way I can. Because really there is nothing to do for it only pray and I have done much of that. I feel like they will come up with the answer to it some of these days with God's help. But it is going to take time and money. That's why we need this Arthritis Act passed so desperately. So there will be more funds to help these arthritis victims.

No one really knows the pain and agony they must suffer. But as the husband of a victim, I can tell you they go through very much. Again I ask that you please act promptly on this Arthritis Act and bring hope to thousands of arthritics all over America.

MARVEL F. FORSTING  
Florissant, Missouri

October 31, 1975

I have been a victim of rheumatoid arthritis for twenty-two years. During that time, I have experienced the agony of this crippling condition, and I know the needs of persons so afflicted. I have been told that there is no cure for this disease and all that can be done is medication for relief. I know that research is going on but that more is needed. Such research would require additional funding which, I have been told, is not now available. Care and treatment of this chronic disease also requires a great amount of money--money which is often not available to patients or to local health organizations.

I urge this Commission to recommend as a national priority the allocation of funds and other resources to attack this dread disease.

BARBARA G. ISHAMS  
CHESTERFIELD, MISSOURI

October 27, 1975

On behalf of the St. Louis Alumnae Chapter of Alpha Omicron Pi, I wish to express our feelings regarding the funding for arthritis and rheumatic diseases.

Our fraternity has worked on both the national and local levels to assist the Arthritis Foundation. Here in the St. Louis area we have donated funds for research; observed and assisted in arthritis clinics; assisted at public forums; and generally helped the Eastern Missouri Chapter of the Arthritis Foundation whenever asked.



We feel the funding is necessary to help in the fight against arthritis and rheumatic diseases. There are four areas of particular concern:

- (1) Professional education
- (2) Public education
- (3) Patient services through clinics
- (4) Research

We urge your support in seeing that the necessary funds are released as soon as possible.

VIOLA ADAMS  
Kansas City, Missouri

October 21, 1975

I am writing in hopes that we (arthritis patients) can get funds for research and for our foundations. I found out in May, 1974, that I had rheumatoid arthritis, my family doctor said he would send me to the Arthritis Foundation, as he didn't know that much about treating rheumatoid arthritis.

I was thankful we had a foundation I could go to and get treatment. Our foundation has given me the best of care and treatment. I am now taking gold shots and it has kept me from getting any more crippled than I am.

Our foundation is in desperate need of a rheumatologist, not many doctors specialize in arthritis.

Hope the Commission can get funds for research and for our foundations soon.

MARY BELANGER  
St. Louis, Missouri

October 30, 1975

I hope I am not too late with whatever small information I can contribute for hearings to be held by the National Arthritis Commission for Federal funding.

I am relating experiences not as a victim of the pain of arthritis, but as a victim of years of observing the anguish of this crippling and extremely painful disease of arthritis.

I found out the treachery of the word "arthritis" because both of my parents were struck with it. My father at age 34, began 20 years of the agony of rheumatoid arthritis becoming hopelessly bent in two, hardly able to walk, even with the aid of crutches. He even suffered the humiliation of not being able to do the simple, taken for granted personal hygiene

things for himself, such as bathing, cutting toenails and dressing, not to mention the many tears and cries of excruciating pain of the smallest movement. He had to be turned in bed, have his legs moved from one position to another, succumbing to the pain that never subsided. He died at 54, leaving his family exhausted from the years of 24-hour a day care, because there was no money and no foundation or government agency to assist. It left me, his daughter, emotionally broken even to this day, and his wife physically and emotionally wrought.

Today, my mother now suffers the pain of arthritis of the spine and even more painful, arthritis of the jaws, reducing her intake of food to strained food, as chewing is most difficult.

I also watched my grandmother suffer from this disease, so I wonder how soon I am to succumb to it, even now having the occasional "tennis elbow" at age 49, living in fear of what may be my future.

It is most difficult to convey the financial, emotional and physical strain on the patients and their families. The impact remains throughout their lives, leaving us all deeply scared. And then there is the torture the arthritis victim himself endures, which is beyond comprehension.

I strongly urge national funding for intense study and research for a breakthrough in giving the countless number of victims some relief and hope for those who dread this painful and crippling disease, and those who are now suffering.

NORMAN A. CUMMINGS, M.D.  
Louisville, Kentucky

October 22, 1975

This letter is a response to your general invitation for comments from the public concerning the hearings of the National Arthritis Commission on implementation of the National Arthritis Act, and is meant to express our feelings regarding overall philosophy in carrying out the Act.

As Director of a new Arthritis Center in Louisville, I have had recent and personal experience in the often frustrating responsibility of raising adequate monies for support of the various activities developing here. A combination of unfortunate events in the United States over the last several years seems to have aggravated these circumstances.

The state of our economy, coupled with apathy or a climate of resistance to many political aspects of our life has resulted, I believe, in a growing number of Americans being unable or unwilling to help support the medical fight against rheumatic diseases.

Meanwhile, inflation has taken its toll in terms of cost of equipment and services, and funding from Federal sources for training and research programs has fallen short of needs since 1967, in my opinion.

It is therefore with optimism that I add my voice to the many others, both private citizens and professionals, in welcoming a mechanism such as

the National Arthritis Act whereby our goals can be better coordinated and facilitated.

Although I am certain my comments will not be original, I would like to make a plea for balance in allocating resources. The present climate has seen emphasis on service at the possible expense of research, and on "goal oriented" rather than "basic" investigation. Perhaps this is linked to a generally anti-intellectual bent in the public eye. I therefore want to simply add my voice to others in asking that the very vital role of research into the basic mechanisms of disease processes--even if they are not immediately connected to rheumatic diseases in the public eye--not be neglected. Perhaps the adage, "The fool looks for the cure, the wise man for the cause," should be stressed now.

In addition to adequate resources for research, the obvious goals of treatment, stress on a team concept in patient care (including various allied health professional activities), and training should be encouraged.

I also feel that mechanisms which encourage various arthritis centers and rheumatology sections to set up specialty wards, located in the department of medicine but devoted entirely to treatment of patients with rheumatic diseases, should be explored. If awarding various monies to medical schools were partially contingent on the implementation of such "arthritis wards," the very real pressure we feel in so-called "acute" city and general hospitals against admitting patients with these chronic diseases would be relieved. It would be a pleasure to admit, treat and study patients with rheumatoid arthritis again without being pressed to "open" the bed for a waiting patient with another, perhaps momentarily more acute, disease. We seem to be one of the few countries which cannot easily hospitalize our patients for chronic rheumatic diseases, unless they be affluent.

Finally, I ask that due consideration be given in your deliberations for support of an ample administrative staff in helping run the various arthritis centers, and maintaining adequate organization and liaison among the various activities in such a center, and the volunteer and government agencies outside it.

I appreciate the opportunity to comment on these aspects to the Commission.



St. Louis, Missouri

November 11, 1975

MRS. RICHARD ZELTWANGER  
Wakarusa, Indiana

October 29, 1975

As parents of a child who has suffered from a very severe case of rheumatoid arthritis for 15 years, we wish to urge that all monies available be utilized to help the victims and possible victims of this painful and discouraging disease.

Our daughter was stricken at the age of six and was affected in literally every joint in her body. Our one great desire through all these years was, of course, that the cause and cure for this disease would be discovered and we would continue to urge a relentless effort in this direction.

After walking only with great pain for nearly eight years, our daughter was confined to a wheelchair for more than seven years. When she went into the wheelchair we were told she would have to be there for the rest of her life. Mercifully, the total joint replacement surgery came into being soon after that. In June of this year she had total replacement of both knee joints and in September, of both hip joints. She has been walking with canes since the 8th of June and looks forward to even better mobility in the future. This has given her and her family a new lease on life, and we are grateful for all of the money, time and effort that resulted in this discovery.

We were fortunate all through these years to have had doctors who guided us wisely. It has been our experience that not all arthritis victims are so fortunate, or perhaps for one reason or another they have failed to take advantage of what is available. It would seem to us there is a real need for more education and encouragement to those who are afflicted. We are not certain what form this should take, (a type of Arthritics Anonymous perhaps?!), but people who are hurting desperately often become too desperate, or they may simply give up. The "quacks" have preyed upon this situation too long and these people need to be made aware (over and over again) that this is not the answer and that they should never give up hope. They need to know there is someone reaching out to them in a personal way to convince them all is not over for them.

Perhaps what we are saying then, is that we urge the bulk of the available monies be put toward discovering the cause and cure, but please keep in mind the hurting people who need to be convinced to "hang in there" until that beautiful day!

H. SCOTT DAVIS  
Louisville, Kentucky

October 23, 1975

The National Arthritis Commission has requested general comments with reference to the need for and the implementation of the National Arthritis Act. This brief response expresses the deep concern of the Kentucky Chapter of the Arthritis Foundation for the strongest possible sources of Federal help in support of the continuing battle against arthritis in the State of Kentucky.

The Kentucky Chapter of the Arthritis Foundation has been dedicated to the causes of patient care, lay and medical education, and research. We have established 5 clinics and a Rheumatic Diseases Laboratory. We have held our eleventh annual Symposium on Rheumatic Diseases for physicians and are initiating our first annual Allied Health Professionals Symposium on November 20, 1975.

We have compiled an enviable record in the area of fundraising. However, voluntary dollars raised cannot meet the need in our state. We must have an effective program that can only be accomplished through the program and services of an arthritis center. We believe that stronger efforts must be made to find a cure through research. We are convinced that stronger efforts must be made to recruit and train more specialists in our field. We are not proud of the minimal help we have been able to provide patients afflicted with arthritis. In the face of our resources to help, the numbers in Kentucky are staggering. There are 321,000 men, women and children with arthritis in our state and over 80,000 of these reside in our larger Louisville Metropolitan Area.

During 1974, as the result of an unbelievable effort in a troubled economy, we helped establish an Arthritis Center at the University of Louisville School of Medicine. We contributed over \$53,000 for the first year of operation and have committed \$35,000 for the second year of operation. We raised almost all of that \$88,000 in one time restricted grants that will not be repeated. We also secured, in addition, a ten-month Home Care Program for many of our children sorely afflicted with juvenile rheumatoid arthritis. We have helped secure strong matching money from the University of Louisville in support of the center and cosponsored with the university a Federal grant request from the released Federal arthritis money that had been impounded. A grant from that source in the amount of \$46,500 meant the difference between failure and success in establishing the center.

Our plea for Federal help through the National Arthritis Act to meet the human needs in our area is not a political concern. Arthritis has been neglected too long and directly affects the well-being of 50 million people in our nation--including 250,000 children. Dr. Norman Cummings, Medical Director of our new center in Louisville, will be writing separately and outlining our very specific concerns. Please let us know of anything that we can do to help the Commission in the fulfilling of their assigned responsibilities.

HAL LEICHARDT  
Eastern Missouri Chapter, A.F.

October, 1975

On behalf of the more than 460,000 arthritics in Missouri, I earnestly seek your support for funding of the National Arthritis Act.

Our Federal Government has a great reputation for helping those groups of people who are unable to care for themselves. In this particular instance arthritis does not care whom it strikes. In this country alone more than 20,000,000 people are victims of this cruel disease. Many

people in our greater St. Louis area have had to discontinue working and spend the rest of their days with needless suffering.

However, there is hope for these victims and others close to them if the National Arthritis Act is fully funded.

In the past ten years scientists have found out more about arthritis than in the preceding ten centuries. Now this progress is threatened. Cutbacks in Federal funds for arthritis have sharply limited research at leading institutions.

Scientists are urgently asking our Federal Government and the Arthritis Foundation to increase their support for grants to find the cause and cure of the nation's number one crippling disease.

No one is immune. Even though we have no cure nor do we know the cause, the Arthritis Foundation through its nationally coordinated research program is working desperately on this problem.

Our goal specifically should be to:

- (1) Expand patient care for victims of arthritis.
- (2) Increase research efforts in our medical colleges.
- (3) Provide much needed public and professional education about arthritis.

I believe in the Arthritis Foundation and what it is doing. After listening to all of the testimony and my thoughts here, I hope you will feel the same and help to bring about funding of the National Arthritis Act.

Thanks very much for your kind consideration.

BERNARD HULBERT, M.D.  
St. Louis, Missouri

November 5, 1975

I treat patients who have third party payments or who in general are unable to afford medical care. However, the cost of chronic arthritis becomes an enormous burden for many patients who need treatment for decades.

Financial aid is necessary for these people. Equally important is the need to find the causes of the many types of arthritis. If this were accomplished, specific treatments could be found and much suffering avoided. Research requires financial backing. There is no reason that many people are cripples because of the lack of sufficient funds to unravel the etiology of arthritis.

I do not care to appear before the committee.



ALAN D. MORRIS, M.D.  
St. Louis, Missouri

Although I will be unable to testify in person at the Commission hearings in St. Louis on November 11, there are issues which I believe to be of major importance to victims of arthritis. Therefore, I hope you will consider the following in your deliberations. Other witnesses will, no doubt, discuss thoroughly the basic needs for training of professionals at several levels to provide care for arthritics, the need for specialized multidisciplinary care facilities, and the necessity for development of better understanding of basic causes and treatment of arthritis. I would like to call your attention to important current deficiencies in our approaches to the problems of children with arthritis and to the present widespread lack of effective participation by patients of all ages in their own care.

It has been estimated that a quarter of a million children in this country have juvenile rheumatoid arthritis and it is known that disease may lead to extensive crippling or blindness. I am aware of only two pediatric rheumatology clinics in the State of Missouri and experience in the pediatric rheumatology clinic in our institution suggests that many physicians around the state are poorly informed about the symptoms (or even the existence) and the treatment of arthritis in children. The result has, at times, been crippling and morbidity which might have been avoided. Furthermore, physical therapy, ophthalmologic consultation and education of the parents seems to have an important influence on the course of these diseases. It appears, therefore, that treatment of children with arthritis could be improved by better education of physicians and medical students and the use of special clinics. I urge the Commission to consider these special needs of children in their recommendations to congress.

Arthritis is, in most cases, a chronic disease and it is generally believed that the long-term outcome for a patient is strongly influenced by that patient's ability and willingness to follow the therapeutic program outlined for him. Traditionally, we have educated physicians and often ignored the probability that patients can better help in their own care if they understand therapeutic principles. We have recently been studying the effectiveness of efforts by physicians and other medical personnel to educate patients and, as a logical extension, the impact patient knowledge about disease has on their compliance with exercise, rest, and other treatment regimens recommended by physicians. It is clear that present approaches are often not effective in changing patient behavior and I urge the Commission to recommend the development of programs designed to improve education of patients and their ability and/or willingness to adapt daily routines to those which improve control of their disease. These programs might include efforts to devise educational programs applicable to patients with different educational backgrounds and in different settings (such as the physicians office) and to evaluate the relative effectiveness of different approaches. Thank you for your attention.

HERMAN D. PERSON, R.P.T.  
Peoria, Illinois

In regard to the hearings to be held in St. Louis on November 11, I should like to tell it like it is in Peoria. I am a clinical physical therapist who conducts a weekly arthritis clinic for the Central Illinois Chapter, the Arthritis Foundation. The needs as I see them are:

- (1) More rheumatologists--we have only one clinical rheumatologist in our chapter area--82 counties. Two recent newcomers are involved in research which we all know is necessary, but the ultimate aim is delivery of patient services at the local level.
- (2) More informed primary care physicians for early diagnosis, treatment, and referral. There must be exposure to arthritis and rheumatism in the medical curricula. Then can follow referral to the rheumatologists for the appropriate patients and referral to the Arthritis Foundation for literature and information on how they can best live with their problems.
- (3) Classes for the arthritics for living with their disabilities and how to prevent and delay deformity as much as possible.
- (4) Prevention of deformity and relief of pain by means of a plastic hand splint our chapter has made available for four years. The splint is made of Orthoplast, costs \$5.00. Orthoplast, costs \$500 to the patient with most of the cost being absorbed by our chapter. It is a shame patients have to travel hundreds of miles for a simple device that relieves night pain and retards deformity. The education of physicians, occupational therapists, physical therapists and others could provide this service to the patient in his community.
- (5) We need to emphasize the possible, the here and the now. Let's do better the things we can do now, while we look to the researchers for better answers for the future.

ANN LEFFERT

The development of the "long-range plan to advance the national attack on arthritis" is the essence of the responsibility of the National Commission on Arthritis and Related Musculoskeletal Diseases. This plan is to include the total scope of arthritis. Speaking through the experience of being afflicted with rheumatoid arthritis, I strongly feel that fundings need to begin to reach the individual arthritic. There are two distinct areas which I feel need top priority and immediate attention. The first area is that which contains the victims of arthritis who are poor. The second area which is as equally important, is direct patient education.

Regarding the poor victim, I would like to quote, William S. Morris, Lieutenant Governor of Missouri at the 1971 Governors Conference on Arthritis:

"The hardest hit are the poor. Arthritics who are fortunate enough to have time and money can sometimes overcome the deficiencies of our health care system by traveling around, sometimes even to a number of different cities and states, finding a path through the jumbled medical maze and putting together their own personal programs of continuing comprehensive care by doctors, hospitals, physical therapists, and other allied health professionals. The poor have no such chance. There is no single pipeline labeled, 'Enter Here.' For the victims of arthritis who are poor cannot step into the system and be channeled through the full assortment of coordinated services they need. In most cases they simply suffer and become partially or wholly disabled."

The status of the poor since this statement was made in May of 1971 has not changed. This is what needs to be changed. We all recognize this great fault in our medical system but what positive action is there that is supposed to be bringing about this change? I offer the suggestion of making the poor aware. This lack of awareness is not due to substandard mentality but simply the lack of knowing where to go for what they need. Women have been made aware of the seven signs of breast cancer through television. If television can be used as an educational media for cancer why not for arthritis?

The second area of patient education is also just as important. This area is of such importance and a prime problem. There are simply not enough specialized professionals in this field. The two specific professionals which I feel are greatly needed are the nurse practitioner and the patient educator. They are able to aid the arthritic to grasp the reality of his disease and the changes which coincide with it. The arthritic may go through some very traumatic experiences even to the point of retreating from reality, merely from lack of understanding of his disease. Arthritis is like a giant roller coaster ride. Arthritis can become almost nonexistent then without notice flare to the opposite extreme. This fluctuation along with difficulty of recognizing limitations caused by the disease, can at times seem almost impossible to cope with.

Although arthritis may bring limitations, deformities, and crippling, the mind and inner spirit of the individual is still alive. Expectations, goals, physical and spiritual needs still exist. I cannot stress enough the immediate financial, educational and psychological needs of the arthritic that need to be met, right now.

FRANCES M. KABERG  
Cedar Hill, Missouri

(Face audience, working papier-mache barbells. Sound affect giving a loud "CRACK." Stop, stand amazed, then speak, "Good God, what have I done?")



The skit you just witnessed occurred in my living room one evening in the fall of 1969.

Never again did I lift the 3-lb. karbells. I knew that I had over-extended myself in a too aggressive physical therapy, trying to build up the strength in a formerly fractured wrist. At home, I had practiced strenuously morning and evening, even to taking those dumb dumb-bells to bed with me; took them to school, too, and lifted the weights in the classroom closest between classes. Apparently, the "CRACK" triggered an unknown factor and threw me into an insidious progressive disease--one of the bastard collagens.

As many of you know, when you have been on-the-rack long enough, you will seek almost any means trying to find a cure or to receive relief from savage crippling. Your better judgment tells you it is fruitless but you keep trying. Hope is eternal. Thus it is, that we may drink alfalfa tea, honey mixtures, and swallow vitamins by the handful. We may ever wear copper bracelets, visit health spas, and try acupuncture. Perhaps we see psychiatrists to help us cope, subject ourselves to beestings, or resort to the 'laying-on-of-the-hands'--all in vain. A man once came to our antique shop and noticed I was having difficulty in walking. He said that he had had arthritis and that I had the cure right in front of me. A pokebe y, by the shop door was in its full autumn splendor, heavy with be ies. "Just swallow three ripe be ies every other day. That's what I do. In a few days, you will be able to jump a rail-fence." I never saw the man again and he did promise to return. Then, there is the farmer who swears that when he has a "rheumy" pig, he just pens him in a mudhole and bakes him there all summer long. When butchering time comes "that pig will be squealing on all fours and ready for market." Perhaps the hot mudhole may be the right panacea. Yes, when you get desperate enough you will try almost anything.

In six years, some 17,480 aspirins have gone down my gullet. Many of you can top that. You and I know that aspirin does little or nothing for severe pain but we continue swallowing them, hoping they will help to curb the inflammation. Research has given us some very powerful chemotherapy drugs and if you are lucky, you may get some relief. Some very nasty side-effects can and do happen. Hallelujah, we rejoice for those for whom the drugs stabilize or a est the disease. Then, there are the poor wretches whose quality of life is bleak, indeed, as the crippling goes on and on. We cry loudly for more and better research.

The 80,000-year-old twisted skeletons of Neanderthal Man show that arthritis and bone infections were common. That's a long long time, baby, for mankind to be so incapacitated. Man, by science, has been shot to the moon and his ingenious warfare devices can wipe man from the face of the earth but we still do not know the causes or have the cures for a number of dread diseases--arthritis being high on the list.

Not for a moment do we think we have any corner on the sufferings of the world nor do we plan on becoming obituary makers for a long time; nevertheless, there are times when we cannot deny that the "happy hunting ground" is an attraction.

As the crying baby gets the milk, let us be heard and move forward in research. We cry, "Find the causes! Find the cures! Let us pitch our canes and wheelchairs into Dante's Inferno. Let us go about our business of living!"

May the archangel wing his way to our prayer rugs!

JOHN C. HOFFMAN  
St. Louis, Missouri

November 9, 1975

I have had arthritis for twenty years. During the past six years I have been treated at the Wohl Clinic in Barnes Hospital. After a thorough physical examination they recommended an operation on my knees, in other words, plastic knees. However, I felt that so long as I could walk, and secure some relief with drugs, there would be no operation.

Three years ago I bumped my right wrist while working as a meat cutter in my own business and the arthritis developed into gout in my right hand. This made it necessary for me to retire from cutting meat and I became a consultant and adviser in my own business.

On the last visit to my physician, in June of this year, it was again recommended that the knee operation be performed. And I was advised that I would wind up in a wheelchair if this operation was not done and I continued walking as I do, as it would throw my back out of line. Since 75 percent of these operations are successful, I decided against it as I might be one on the 25 percent side.

Many remedies have been tried by me in the past twenty years and so far I have had the best results from a diet in Dr. Campbell's book, Relief of Arthritis Pain in Seven Days. On July 1, 1975 I started this special diet and at this time I still have arthritis but most of the pain is gone, and my weight is down twenty lbs. -- 5 feet 9 inches and weight 170 pounds.

My schedule includes: Exercise thirty minutes each day; nine holes of golf two to three times a week, and swimming in a heated pool four to five times a week, one hour each day, covering 70 laps or 1750 yards.

Since I have been on this diet my blood pressure is again normal and I do not seem to tire so easily. And I believe one of the most helpful things is swimming--water is healing for arthritis.

I hope this letter will help someone else who suffers from arthritis. On my last birthday I was sixty-six years young.

GEORGIA L. LIGHTFOOT  
St. Louis, Missouri

November 3, 1975

Thank God for our chance to speak out. I had been going to doctors for years, the last one before I found Dr. Crossman, I don't remember his name but he was over Lindell Trust Bank at 2745 North Grand. He said I



had water on the knee but never tapped my knee, only gave me pills. Under this medication, I went home from work one Thursday night in 1955 still with all the pain and my knee almost as large as a small watermelon.

So I called the exchange and they recommended Dr. Crossman. He sent me right to Missouri Baptist Hospital. I was there three or four weeks. He tried cortisone and I was allergic to it, so he gave me medication which did help. But dates are hard to remember. I am sure it was 1955 when I started with him. I worked with him in every way I could and I am sure he gave me every test there was. His diagnosis was osteoarthritis.

Dr. Crossman gave me a very large shot of medicine in my knee which took away all the pain for about 1-1/2 years. During this time I really enjoyed fishing and other activities.

When I first started going to Dr. Crossman, I went three times a week as a general rule. That was \$15 per week for nine weeks and my medicine was \$19 per week. Then they sent me to Firmin Desloge Clinic. The prices there were outrageous. I had to pay more for my medicine there than at Medicare. But, thank God, since we are now allowed to deduct medicines from our income tax, I have found a doctor and pharmacist that will cooperate, and I save a great deal on 65 Darvon compound and Desoxyn 15 mg. If it was not for them, I could not even walk from the bedroom to the kitchen. They are \$29.95 but it is a three-month supply of medicine. Since 1954, we have gone through \$24,000.

The doctor asked me if we had elevators at work, and could I get someone to take me up and down. The Vice President saw to it that I did use the elevator. I was only allowed to walk two blocks a day. All these years I was in and out of hospitals. No one knows the pain I have lived with.

However, his nurse retired at this time. I had quincy of the throat which rotted my tonsils, and he said anytime I had to come to him, to come, but it then became difficult for me to drive and I called his new nurse for an appointment. She suggested that since I had moved to south St. Louis, I should try to get a doctor in that vicinity.

A doctor on Grand Avenue was recommended to me but I could not afford him. He said I had heart trouble because my feet were so swollen. Then I was sent to another doctor who would have nothing to do with Medicare, and I remembered him saying I needed a bone doctor, so that is where Dr. Lottes came in.

In 1967 I got Dr. Lottes to operate. I do not remember anything of this. For some reason I go into a lapse of memory. I was in a long cast from hip to ankle, and my husband had two nurses with me in the hospital. After Dr. Lottes operated on my first knee, I went into shock and coma and almost died.

I was in the hospital 36 days and the last week I was walking with a walker. When I got home, I was still in the hip-to-ankle cast for three weeks, and then he took the cast off. When I asked him when I could drive my car, the doctor said, "I figure next month." I went out once to the



doctor in a cab, and after that I went out one day to the doctor and told him I had driven out to him. He was astonished. The reason I was spun on to drive my car was that my daughter was in the hospital and I had to get to her. I cannot count the times Dr. Lottes had me out at the office. He said I really pushed to get going. My diagnosis at this time was deterioration of the bone and spine.

I asked Dr. Larson if those gold shots would help me. He said I am beyond any arthritis medications. Thank God for what insurance we had. It helped but certainly did not cover the expense. I donated all I could, but with all the expense of medicines and operations and hospitals, and having a daughter in a home because of mental illness, it is hard now.

However, now Dr. Kuhlman operated on my right knee. All the stitches came out and I had to take care of it myself. I was in his office twice from the 15th of November I think.

I take about 240 Darvon Compound at the rate of three every two hours. They had me on Percodan Demi. I got two prescriptions September 13, 1974, for \$38.70.

I have been trying to get hold of Dr. Stein from Barnes Hospital. His office visit costs \$20. Dr. Upshaw from Corpus Christi, Texas, told me there is an operation called "geomedic knee," after which you can walk with no pain at all. Of course I have no way of knowing how I could spend that much, after having already had both legs operated on. I don't even know if I could go through it again. The difficulty is I know of no one who has had this operation.

I am never without pain and Dr. Crossman said that I would probably end up in a wheelchair. I have lived ten years of hell since 1955. If someone could get Dr. Robert Crossman to give me a shot in each knee, I have confidence in him, but when his nurse told me to get a doctor in south St. Louis, I did not know what to do. So this doctor asked for my papers and maybe Dr. Crossman did not know about our difficulty. I know he gave me some relief, and I think he is a wonderful doctor.

I could not stand this pain without 65 Darvon Compound, Desoxyn and Tuinal.

God bless those little children in Children's Hospital!

NANCY ODEND'HAL  
Columbia, Missouri

October 24, 1975

I am writing you in relationship to the National Arthritis Commission hearing that will be held in St. Louis on November 22, 1975. I am a medical social worker at the University of Missouri Medical Center in Columbia, Missouri and I have been working with the Arthritis Center at the university for one-and-one-half years. I have had an opportunity to

talk with many patients with arthritis and have become aware of many social problems that exist for these patients.

(1) I have talked with many people who have held jobs involving physical labor, for example, working as a waitress or as a construction worker, who are no longer physically able to perform their jobs. The assistance provided to arthritics by the Department of Vocational Rehabilitation in Missouri is minimal and grossly inadequate. The reason for this seems to be lack of knowledge of ways to help on the part of the vocational rehabilitation counselor--certainly not an unwillingness to help.

(a) I see the need to develop a list of the types of jobs that people with deformities from rheumatoid arthritis can perform. I am particularly referring to those arthritics without a college education.

(b) I also see the need to develop a registry of jobs that are available that people with rheumatoid arthritis and osteoarthritis can perform. I think this should include talking with employers and actively encouraging them to employ half-time or part-time workers, since many people I have talked with who have arthritis could work four hours a day, but not eight hours a day.

(2) Financial worries affect many people with arthritis as they are unable to continue working without doing severe damage to their joints. Yet they are not considered totally disabled. Thus, they have been turned down for Social Security disability payments. Many arthritics do not purchase needed adaptive equipment for the home, such as a raised toilet seat, because they cannot afford it. Voluntary agencies in Missouri such as the Easter Seals Society have been helpful in providing needed adaptive equipment for some patients, but they have been unable to meet the extensive needs of Missouri citizens with arthritis.

(a) I would like to suggest that we need to provide the needed medical care and the needed adaptive equipment for those arthritics who cannot afford to purchase it themselves.

(b) I think we need to insure that the person with arthritis has a guaranteed minimum income while providing help to this person in finding appropriate employment.

(3) Many patients with arthritis are homebound and many of these people are depressed and feel hopeless about their condition.

(a) I think we need to provide outreach services, perhaps by medical social workers who have the time to make the needed home visits. The purpose of the home visits would be to provide emotional support and counseling services and to make the arthritic aware of the community resources already existing that might provide services for him.

In my work at the Medical Center as a social worker, I have come across no other group of patients that have as many unmet needs as the patients with arthritis. I sincerely hope that the National Arthritis Commission hearings will bring many of these needs to light. I realize that there is a need for intensive research efforts to discover both the causes of arthritis and cures and/or treatments for the various forms of arthritis. I have not spoken to this area because I am sure that there are many physicians who are a lot more familiar with the needs in this area than I am.

Thank you for reading this letter.

JEANNE E. BREWER  
Kahoka, Missouri

October 28, 1975

Twenty-five years ago a demon named arthritis invaded the physical being of a 20-year-old college student. Since that time, I, the former student and now a wife and mother, have been put through a living hell of constant pain or discomfort, unable at times to do the simplest of household tasks. Although pain is always present somewhere, I have put on a terrific front--keeping civically busy, keeping books for my husband, doing photography (when the camera doesn't become too heavy), substitute teaching, and reporting for an area newspaper.

You see, my mind hasn't been affected. It seems at times people think that goes with it. "Oh! what a shame. You have arthritis." That's how good my front has been.

But the last straw came last summer when I applied for a position at our local school. It was getting late and they couldn't seem to find anyone for a position I was certified for. Since I felt so much better while teaching and doing something, I thought I'd give it a try. During the interview with the principal, he inquired about my arthritis and pointedly asked "Just how many times do you not feel like getting up in the morning?" Well, I didn't exactly tell the truth, but I didn't lie--I said "I always feel so much better after I've been up one-half hour and especially if I know I'm needed on the job." I didn't get the position and I'm sure this was possibly one of the reasons.

We must do more research into the "why" of thiscrippler, but we must also educate the public more about the facts--arthritis is acrippler of the body, but it doesn't blow the mind. People are still capable of using their intelligence. I don't plan to just sit down and say "I have arthritis. I can't do anything," just because I hurt, but will employers be willing to take a chance on us? Many of our minds are still sharp and we want to be doing. Why can't we have the same opportunity as any other handicapped person? Come on, let's face it. We are handicapped. Yet when we go in for disability under social security we can't get it because we haven't worked enough.

I plan to fight to keep moving. As special events chairman for Clark County, I plan to organize more bicycle marathons, bake sales, auctions, etc., to raise money for research. I plan to keep educating our people to



the fact that arthritis affects the body, not the mind and I hope to fight it to the bitter end. I'm going to battle this demon with my faith in the Great Physician, Almighty God, my early physician, Dr. Hagemann, and hopefully, a little help from the government for further research.

NORBERT W. AND MARY C. ORF  
Florissant, Missouri

October 31, 1975

We were informed by the Arthritis Foundation, Eastern Missouri Chapter, that the National Arthritis Commission is coming to St. Louis on Tuesday, November 11, to hold public hearings.

We will not be present at the hearings but would like to enter a statement for consideration by the Commission.

There is a great need for more research, doctor training and public education in regard to finding a cure, prompt diagnosis and treatment of persons afflicted with the disease of arthritis.

As parents of a six-year-old child with arthritis we hope that with the Federal Government's support this great need will become a reality. Then, the 250,000 children in this country with JRA (juvenile rheumatoid arthritis) may grow up to be useful, productive citizens in our society.

Polio was conquered in the 1950's. It is our hope that the cause and cure for arthritis may be found in the 1970's.

CHRISTINE COOPER MOON  
Fayette, Missouri

October 21, 1975

I, Christine Cooper Moon, have had rheumatoid arthritis since 1924 as a young wife and mother of a two-month-old baby daughter.

Now my husband and I have observed our 52 years plus with "Arty" (R.A.), and, if God is willing, will on December 24th, 1975 enjoy our 53rd anniversary. I am very, very interested in any program to help fight this crippler, since my last 34 years have been in a wheelchair. I am unable to move from the bed to chair or vice versa, can neither bathe, dress or touch my own head or toes. I have never allowed myself to question WHY, or grumble of my aches and pains--they are there all the time, believe me!

I am richly blessed with my dear husband, and so far able to keep good help, allowing my husband to continue to run his own business, he has owned since 1936.

But now one of our 5 grandchildren has developed rheumatoid arthritis--started when she was 7 years of age--spent some time in Boston General Hospital. For time being it has seemingly been under control most of that time and she is now a lovely 14-year-old girl, living with her parents in New York State (near Cazenovin).

This is for her, and the many, many other children, and young adults I make my plea for help to find means of stamping out this terrible wrecker of bodies. Not only does it wreck the victim's body, it is or could be a wrecker of those dear ones near.

I also think provisions should be made to help those requiring constant outside help. Costs can run very high.

I cannot use a typewriter, or reach very many inches from my body. Hope this will be readable, and at least I'll know I've tried, to help advance the interest of those who, like you, are trying to help in this work.

I'll enclose a picture of my husband, and I, with one of our daughters, and husband of K. C., Mo., taken in our home April, 1975.

I had a book published in 1955. I also write poetry, and we have many friends.

MRS. H. BAUMGARTNER  
Pacific, Missouri

October 28, 1975

I received a letter re N. A. C. public hearing to be held in St. Louis on Tuesday, November 11, 1975.

I am very interested in any work done in the fight against arthritis. However, I have degenerative arthritis of the spine as a result of a severe burn. I am quite crippled. Also transportation is a problem. Therefore I will be unable to come to the meeting.

I would encourage any effort being made to eradicate or even a est or relieve this disease.

KATHRYN BUGGS  
St. Louis, Missouri

October 29, 1975

Four years ago I was in an automobile accident and received a T12 Vertebral break. After which I developed arthritis of the spine, neck, right shoulder, and arm. A year later I began to have severe pain in both hips.

After X-rays I was diagnosed as having oesteoarthritis of both hips. The bones did not respnd to treatment and I was put on crutches.

A few months later I was told that the right hip had degenerated to such an extent that it was half gone and that I needed a total hip-joint and socket implant.

I had the right implant in March, 1974, and in August the same year I had the left. Both surgeries were done here in St. Louis at Barnes Hospital.

I'm writing this letter to bring attention to the positive aspect that something can be done for arthritis sufferers.

I never used a walker or cane. I walk independently and get along fine. I am so thankful that this surgery could be done and sincerely hope that your bill will be passed so that the many people with various forms of arthritis will be able to have surgery, medications, therapy, and whatever else is needed to make life a little easier for them.

ARGUS W. DAVIS  
Overland, Missouri

October 29, 1975

I, Argus W. Davis, am very interested in your desire to help find a way to control this dreadful and almost unbearably painful disease which I have. It is called osteoarthritis. I am glad to know there is someone who cares and is trying to do something about it. It may not be completely controllable in my time but in the future it will come about.

And I am very glad Mr. Ford has come to realize that this is very urgent. Especially to us who have the symptoms of this disease.

I also would be glad if I could be of some help in the fight against it. I certainly hope that every person who has it and who sees and knows the people who do have it realizes the need of its control. I hope this short letter will help someone.

IDA M. WILLIAMS  
Kansas City, Missouri

October 28, 1975

It was early in 1972 my right hand was swollen and very red. My doctor said it was arthritis, the crippling kind, so he started treating me and suggested that I use paraffin. It seemed I would be relieved for a short time, but the severe pain and swelling would occur more often. My doctor said that he honestly didn't know what to do next so he suggested that I contact the Arthritis Foundation as they had very good doctors also the newest information on treating this disease. We called the Arthritis Foundation and made an appointment. The doctor interviewed me, getting complete history, also medication I was taking. He prescribed medication, also traction for my neck. Another doctor prescribed in the home treatment for the neck, also mittens to wear on my hands at night. I never missed an appointment at any time.

In February of 1974 we talked to the doctor about the "gold" treatments. He explained the treatment, so I started taking those. I take them every four weeks plus four Persistin a day. I am able to do the work necessary in keeping the house and I also work with the flowers and help with the yard work. I do not have the attacks as I had before going to the Arthritis Foundation. All of the people involved at the Foundation are very kind, helpful and have the knowledge to help in any way. I am very grateful for this treatment.



AGNES DYE  
Ozark, Missouri

October 24, 1975

It is my understanding that the National Arthritis Commission will be holding a public hearing in St. Louis on Tuesday, November 11, at Busch Memorial Center.

Due to health problems, I cannot attend in person, however, I would like to be represented by letter. I am personally interested because we have a daughter who has suffered from rheumatoid arthritis for more than twenty years. I, also, lost a brother from this dreadful disease.

I feel that the appropriations for this disease have not been sufficient in the past.

I have written to Congressman Gene Taylor about the need for more money. It is my understanding that the appropriation will be increased to \$148,000,000. For this we are very grateful. I feel that it would be cheaper for our country to find the cause and then a cure for arthritis, since in 1970 the cost was \$9,200,000,000. This was for medical care and lost wages. Total work days lost--14,500,000.

We live near Springfield, Mo. This town has only one rheumatologist at present. We cannot expect him to do justice to the arthritics in this territory. Other doctors have their monthly magazines but we must remember they are very busy.

Our need in Springfield is that we have some localized point for the arthritics. We are in desperate need of more rheumatologists.

We hear that we may get a new building in Springfield to be used for health, education, and welfare.

If we should be this fortunate, I would hope that some portion of it will be used for arthritis patients.

Also, that it would be staffed with several extra doctors for treating these patients.

I hope your new National Arthritis Commission will check the existing conditions and prepare a better plan for these suffering people. I believe they deserve help. Now they are sent to just any doctor that can work them into his busy schedule, though it is not his specialty.

Please help, if it is possible for your Commission, to work this into your plans and programs.

Thanking you in advance for any help you may be able to give us.

St. Louis, Missouri

November 11, 1975

NINA ELDER  
Ferguson, Missouri

October 27, 1975

I wish to say I would like a national funding for arthritis--only the ones who have it or their family know the agony of arthritis.

My letter will be short as arthritis is in my hands and it is hard to write. My thumbs of both hands and my index finger go out of joint and writing is quite a chore. My hands are stiff in the mornings and things such as using a bobby pin, unscrewing a cap, breaking an egg, among other things, are a chore to do. My legs, too, are affected and sometimes it's hard to get around.

I wish something could be done for arthritis and I know others who wish the same thing.

CAROL BAKER  
St. Charles, Missouri

This letter is pertaining to the upcoming report to Congress regarding the National Arthritis Act.

I am not personally afflicted with this crippling disease, but my beloved sister is. It is out of love and concern for her and millions of people suffering from this terrible, painful disease that I am writing this letter. My sister has suffered with this terrible pain and been crippled for sixteen years, she is now thirty-two.

I hope and pray that through research and funding she and others can be helped to have a few years of their life without so much pain.

Thank you for reading my letter. I couldn't sleep tonight if I didn't do all I could do to help my sister, hopefully this letter could help.

ETHEL E. SEARS  
Lee's Summit, Missouri

October 20, 1975

I have suffered from rheumatoid arthritis for some three years. I had this disease for about four months before it was discovered what was wrong with me. My feet, hands and knees were badly swollen, had red inflammation spots and I was in much pain.

I was sent to the Arthritis Foundation, 2727 Main St., Kansas City, Missouri 64108. The dedicated staff there took much interest in my condition. My left knee was most painful and stiff, a shot of steroids was injected and I received much relief. I was given gold shots and Persistin; urine and blood was closely checked.

I am still under medication, but medication is much less. I have less pain, am less stiff and am able to take care of myself. Of course at times I feel better than at other times. I am now able to wear shoes in comfort.

I deeply appreciate the care the Arthritis Foundation has given me and their help.

I hope everyone becomes aware of the pain and crippling of this disease and the wonderful work that the various Arthritis Foundations are doing and will help them financially to conquer this disease. I also hope because of the serious shortage that more doctors will consider becoming arthritis specialists.

EDWARD E. MOORE  
St. Louis, Missouri

October 28, 1975

It pleases me very much to have a few words to say in behalf of the Arthritis Foundation before the National Arthritis Commission which will be held in St. Louis on the St. Louis University campus. We all know that arthritis is a crippling disease which has hurt a lot of good people and I do not think our government has done its fair share by our people. Moreover too long and too little and too slow, the Arthritis Foundation should not have to get on their knees and beg our lawmakers for help. What do you think?

ALTA B. HILL  
Kansas City, Missouri

October 26, 1975

My name is Alta Beatrice Hill. I was born in 1915, January 8, in California, Missouri, Montineau County. I and my twin sister were raised by our grandparents. In 1936 my sister and myself went to Chicago to visit our aunt and uncle, my aunt ran a beauty parlor. One day I helped her do some of the ladies' hair, somehow I infected my left hand, because in about a week my hand began to swell. My aunt who was a registered nurse, gave me treatment.

I was in pain and lost weight. I had to sleep with my hand in a chair on a pillow because it was so stiff and swollen. My aunt became worried about my being around her three-year-old nephew. So they took me to Cook County Hospital after three weeks of pain. I had been holding my hand palm up so that's the way the doctors put it in a cast, it stayed on for seven weeks.

When they took the cast off they found that the leader had drawn back, so the doctor told my aunt and uncle to send me home because I had arthritis and the climate there was bad for me. When I got home I went to Latham Hospital in California, Missouri. My grandparents could not pay, so the county paid.

Doctor Latham broke my wrist and put it in a splint, or half cast. I would soak my wrist in liniment and go back to the hospital for treatment. My grandparents moved to Kansas City, Missouri. My grandmother became ill so I came up in 1940. I had been taking treatment from 1936 to 1939 in my home town. In Kansas City, I got a job in an overall factory, it lasted seven months but they found out I had a crippled hand so they let me go. From then on no one would give me a job because of my hand.

In 1944 I married but for four years I had not had treatment for my hand. It was not until 1945 that I started treatments again, I had gone



St. Louis, Missouri

November 11, 1975

to Jackson County General Hospital to have my first child. Dr. J. Garden started therapy for arthritis. I had treatment from 1945 to 1960 at General Hospital. In 1960 Drs. John Webb and Ball operated on my feet for bunions.

They operated seven months apart on one foot at a time. They placed screws in my feet so that I could not take therapy any more. Came under the care of Dr. James S. Johnson from 1960-61 to 1971. Dr. Johnson got me into the Arthritis Foundation in 1974 and am still with the foundation. Since starting at the foundation I've had the screws removed from my feet and I have been walking better.

My family has been very natural because I have had arthritis even before they were born so it was and is not a very strange thing to them. But they have noticed the difference in how I walk and are very happy about it and they hope that I will get even better. I can even use my hands more easily since I've been to foundation. Which is the best of my improvements which I am happy for. I hope that others are being helped as I am.

DORIS WYNN  
Skidmore, Missouri

Have had arthritis of lower back for several years going from one doctor or another. They don't know what to do. They say take aspirin and keep going. We need some trained specialists and money for research.

That's my story in a nutshell. I am age 66.

MRS. BERNARD WISS  
Kahoka, Missouri

October 29, 1975

I received your letter yesterday. Sorry I will not be able to be present at the meeting for arthritis.

I only hope and pray that Congress will make the act a reality.

My daughter, Mary Frances Curley, has rheumatoid arthritis and I know the pain and suffering she has endured the last few years.

I will be praying for the Commission to be able to help the many who are suffering from the terrible pain of arthritis. Thank you for your letter and sorry again I will not be able to come to St. Louis at this time.

ESTHER THOMAS  
Palmyra, Missouri

I am not very good at putting on paper what I have to say but I will try.

I have been disabled with rheumatoid arthritis for five years and each year I get worse. I would be happy for myself and anyone who has any form of arthritis if a cure could be found or anything that would take away some of the terrible pain that goes with it.

I feel as if arthritis is as necessary for research as cancer or any other disease that is taking our citizens.

People don't seem to realize how serious arthritis is.

We have a good many people in my town who have arthritis but they don't seem to respond to a drive for arthritis.

I have arthritis over 90 percent of my body. I just have to hope and keep moving so I won't be in a wheelchair for the rest of my life.

I could talk a lot better than I can put on paper what I have to say.

I am Chairwoman for Arthritis in my town of Palmyra, Mo.

RAY HECKENDORN  
St. Louis, Missouri

October 30, 1975

I am very sorry that I will not be able to be present when you are in St. Louis receiving public testimony on the problem of arthritis. Our national board which meets only twice a year is in session that day and there is no way for me to absent myself from that meeting. Because of that I am writing to you expressing my concern in the area of arthritis.

While at the present time I am not afflicted with this crippling disease, I do have several friends who are suffering with arthritis and on their behalf and behalf of the large number of people in the United States who are suffering this way, I wish to express my concern and to encourage national support to help solve this problem of crippling arthritis.

One couple I know have a grandchild less than three years old who is already severely afflicted with arthritis. I was appalled as I began to look into this to realize that this is the number one crippling disease for children.

rr middleaged people like myself. Mr. Wartofsky, I do not have the answer for this, but since I do work with a non-profit organization which attempts to meet the needs of people and has been doing so for 88 years, I know some of the pain of suffering and encourage you and your Commission to look seriously as I know you are doing into every new possible way to help fund more research on arthritis so that we might find the breakthrough not only in the area of research but might also have more funds available to provide pain relieving treatment for those who are now suffering.

Thank you for taking the time to read this letter. No reply is necessary on your part as I know you are busy, but I did want to share

St. Louis, Missouri

November 11, 1975

with you my concern. May God bless you in the overwhelming task which is before you.

ANNA COLONA

As an individual afflicted with the crippling disease of rheumatoid arthritis for 31 years, I am concerned with your struggle for the fight against arthritis.

On Tuesday, November 11, I will be at the public hearings at Busch Memorial Center in hopes to appear before the Commission with my testimony.

I am a victim who goes throughout each day with horrendous suffering. I have gone through five operations in the past two years with hope of some relief, but only to find that I ache more and become stiffer with each operation.

My last operation involved removing a large portion of my right leg that had much diseased bone and replaced with metal and plastic. After nine months I still have a stiff knee and walk in much pain.

I am in great support of your campaign and will do everything to help in your efforts.

SANDRA HAYES  
Maryville, Missouri

October 21, 1975

My name is Sandra Hayes. I live in Maryville, Missouri. I am a 38-year-old housewife. My husband Jim and I have been married 14 years last June. We have two sons, Troy age 13 and Todd age 12. Eleven and one-half years ago I became a rheumatoid arthritic. My sons are not old enough to remember me any other way. It is very hard to try to explain to anyone, all of the trials and tribulations an arthritic and their family goes through. There have been many many days in those 11 years when I have had to struggle to get up and do only the very most necessary duties around the house, and of course lots of days when I just couldn't do even that much.

That really is hard to take too as I have always been a person who liked to keep my home and clothing, etc., up in shape. I like everything neat and tidy. Thanks to my husband though things have never gotten too far behind.

He is so good to help me out, and so understanding. The boys have been real good too, considering their ages. I'm sure it's hard for them to understand, at times, why we can't do some of the things other families do together. There have been some times when I have done things that I didn't really feel well enough to do, but that's life I guess. I am sure my boys still have a longing to do some of the other things we can't do because of me. Of course that bothers me. An arthritic suffers mentally as well as physically. You feel at times like you are such a bore and



burden to your family. You have times of depression and blues when you just feel like giving up. When I am in public I put on a front and am a fairly happy acting person, and I try not to bore people with my misery. But then when you're at home you let down with your family.

They are the ones that really see your bad side and that you take things out on, so you see they suffer too. Arthritis tends to change your disposition from good to bad if you don't try to guard against it all the time.

Our family doctor found that I had rheumatoid arthritis about six months after I was first bothered. It started in a knee then moved around from joint to joint. I had real red hot swollen spots on the joints along with excruciating pain. Then it would go away, and then in a week or so it would be in another joint. Then after about 2 or 3 years it settled into most of my joints except my spine. Then occasionally I have an acute attack of the inflammatory kind in a certain joint. I have had a lot of damage and destruction in a lot of my joints especially my legs, feet, wrists and hands.

I have been on aspirin since the beginning. I take 18 a day now. When I had the acute attacks my doctor put me on some Butazolidin, Indocin and occasionally a shot of cortisone if nothing else would help. My doctor has always been very cautious with cortisone. Of course I have spent the usual amount of time groping for help, by going from here to there trying new doctors, etc., that people would tell you about. Then you finally wise up and realize that your own doctor really has known what he's doing and has your best interest at heart.

In January, 1973, our doctor suggested that I go to Kansas City to the Arthritis Foundation and see if they might be able to help me some. I have been going ever since. They started me on the gold therapy at the beginning, and it has kept my arthritis controlled quite well since, until about 10 weeks ago. I started flaring up again then. I am still on the gold, but they are trying to find a medicine that they can give me to settle it back down. I am sure they will come up with something if it is at all possible. They have helped me considerably, but of course, they don't have all the answers yet, and I'm sure they probably won't have without lots and lots of research. I pray that you will make it possible for them and others like them to have the necessary funds and needs for the research.

Right now my hands and wrists are my trouble spots and of course my legs and feet are never very good. My left knee is stiff and will not bend backwards, and is quite painful and unhandy as well. I am a tall person and my long leg is always sticking out in the road, at church, ballgames, in a car, or wherever you go, it is a genuine nuisance. But at least thank God I can walk even if I do have to limp and hurt some. There are many people with arthritis and other crippling diseases that would like to walk even this well. No one but another arthritic can possibly know what you suffer when you have it. But, again, I plead for this Arthritis Act to be adequately funded so that the millions of people suffering from this terrible disease may have some hope.

I have learned so much more about arthritis since I have been going to the Kansas City Arthritis Foundation. I pray that everyone will have the chance to have access to this kind of help and care in the very near future.

BERNICE C. HENLEY  
Jefferson City, Missouri

October 30, 1975

Since I obviously do not have available data on needs of the Arthritis Foundation on a national basis and since it is equally obvious that general information is readily available to you, I will confine myself to writing about that of which I have firsthand information.

I am an arthritis patient. I have been an inpatient at the research and treatment center in Columbia, Missouri, on three occasions within the last three years.

Speaking from a purely personal standpoint, I am deeply concerned about the need for continued and intensified research into the problems concerning the causes and treatment of various types of arthritis. I cannot take most medications normally used in treatment because of acute allergy reactions, even to aspirin compounds. Pain is bearable, but life would be much more pleasant, I believe, with relief therefrom.

While a patient in the center at Columbia, I became acquainted with a mother of three children. She had a problem in the neck area that was causing considerable loss of use of her right hand, in addition to the pain that accompanied the situation. She also had a peptic ulcer to contend with, making normal treatment for arthritis very difficult for her. Use of steroids and aspirin was hampered by the presence of the ulcer.

Still another patient was a beautiful, intelligent young woman who had learned too late of the center and arrived there only after some deterioration had occurred in her right hand. She is being helped with a severe rheumatoid arthritic condition.

In fact, all three of us have been helped. But there is so much yet to do, so much to learn about why does arthritis develop? Why are these persons affected badly and those not so severely? (Almost everyone is affected to some degree by an arthritic disease before his life ends.) What can be used on children that will not disturb their growth centers? What can be used in lieu of commonly used drugs today, those that cannot be tolerated for some reason or another by some patients? How can crippled hands be reclaimed? How can a man avoid the acute spinal curvature he is peculiarly subject to?

I would not imply that there is any lack of concern, lack of able treatment, by those working in this field today. What I am saying--by no means implying--is that these dedicated persons need help that can come only from financial backing. Money is needed for expanded research centers, for more laboratory facilities, for more training of personnel in the field.

My interest is pressing. I have arthritis now--osteoarthritis. It does not kill; I hope I shall not have too much disfigurement. But I do have pain. I can live with it. Can you?

Very few persons will live a normal life span and not have one of the collagen diseases. The problem of control, then, is not for the benefit of a small segment of our population, but for virtually every person alive today. We do have the longest life expectancy in the history of mankind, and with each year of longevity the percentage of persons affected with arthritis or a kindred disease rises.

Where can money for medical research be spent to better avail for the greatest number of people than in the field of arthritis ailments?

AMELIA COX  
Shawnee Mission, Kansas

October 28, 1975

My name is Amelia Cox. I am 35 years old and have a husband and 4 children. I have had rheumatoid arthritis since I was 21. It is not in bitterness nor with vindication, but with hope and courage for the future that I relate my story to you.

I was a farm girl, active and ambitious in my younger years. There were chores to do, horses to ride, games to play and good family times. I loved all kinds of sports and participated in them avidly. Now, I sit on the sidelines and dream.

I married at 17 and began to make a home for myself and my husband and to raise a family. I can't remember exactly when things started going wrong, but I recall constantly being tired and feeling run down. I tended to think of this as the stress of taking care of a home and 3 small children. Shortly after the birth of my daughter in 1961 I began having terrible pains in my feet. Slowly the pain moved from my feet to the other joints of my body. I went to my family physician and was treated with aspirin and some other drug but without much relief. A year and a half later I couldn't walk or even get up out of a chair and I started noticing a change in my hands and feet which were becoming grossly disfigured. In August of 1963 I was hospitalized and it was then that I was told that I had rheumatoid arthritis. I was given Plaquenil and cortisone, but it didn't seem to help. My doctors kept telling me that it took time for the drugs to take effect so I took the attitude that the pain and crippling was just something I had to live with.

In 1972 one of my relatives convinced me to go down to a health spa. I guess when you are desperate you will fall for anything because you really want to believe that there is help. The people at the spa told me that they could greatly help my arthritis, and talked me into signing a contract that same day. They wouldn't let me call my doctor to ask him about it, but they told me that they would put in the contract that if my doctor said it was bad for me that they would not make me pay. This was not the case, however. They said that I would have to pay. It was then on the advice of my physician that I called the Arthritis Foundation. It



was with their help through Mr. Waller and their legal department that I got out of paying the contract.

In December of 1972 I went to the Arthritis Foundation for treatment. They started me on gold and some other drugs and in 1973 they suggested surgery for my badly crippled hands. It took a year and a half after that but I finally began to get some relief. Thanks to the Foundation, today I am able to lead a fairly normal life.

The cost to us financially was small, however, compared to the cost of those nine and one-half years of suffering. Not only my own, but that of my husband and my children. Because of my arthritis, a great burden was placed on my family. My children have had to grow up independent because their mother was not always well enough to do most of the things that other healthy women can do for their families. Yes, the price they have to pay is a great one. It is not easy to have to tell your children that they can't do something, or participate in some event because their mother is not well.

There needs to be more places like the Arthritis Foundation where people can go not only to be treated, but also to learn about their disease and how to cope with it. If there had been enough trained doctors, and a better informed public I may have been able to prevent the pain and the crippling. It took me 10 years to begin to get some relief. Ten years too long.

The great potential the National Arthritis Act has if funded properly will give a ray of hope to those who suffer so badly mentally as well as physically with arthritis.

I know that there is no easy answer, but I do know that it is going to take money to pave the way. As a taxpayer I resent the negligence of the government when it comes to the millions of dollars they lose every year in lost wages and disability payments because they don't help the arthritic.

It is my hope that the Commission will consider the plight of the arthritic in a personal way as well as a monetary one. We are people, not just some statistics written down on a piece of paper.

With the proper help maybe some day, somewhere, some other mother with rheumatoid arthritis will not have to go through what I have gone through. With the proper help and understanding of the total problem maybe some day some other mother who has arthritis will be able to raise her family, the most precious of all possessions, with a clear conscience and live life with them instead of having to sit on the sidelines and dream.

St. Louis, Missouri

November 11, 1975

SISTER MARY HENEHAN  
St. Louis, Missouri

November 4, 1975

Due to the lifesaving measures for the elderly, their longevity has increased. A need for assistance in caring for chronic diseases arises since the elderly are affected the most. Here are a few statistics in the population of the City of St. Louis. In 1950, 9.38 percent of the total population were 65 and over. In 1970, 14.66 percent of the total population were 65 and over.

I strongly recommend that services to arthritis patients be supported by the Federal Government.

The sixty-five public health nurses on our staff often see elderly patients in their districts who have arthritis and there are no resources in the community to assist them. We feel that this is a serious public health problem and we are glad to see that the Arthritis Society is taking some measures to assist these people.

ALBERTA GILLESPIE

October 21, 1975

I am an arthritis sufferer, and if writing this letter will help to get someone to see and understand the pain and suffering that our conditions put us through then maybe hearts will open and see that we, too, need funds to help us be at least a little bit closer to our goal of feeling that we too belong in this fight to combat crippling diseases.

I have been suffering with rheumatoid arthritis since 1967 and, not knowing what to do went to doctors who thought they could help me only prolong my progress because they didn't know how to handle my type of sickness. Yes, they gave me medicines that would help for a little while from pain but when it wore off I was in greater pain.

Finally I went to a doctor that told me he couldn't help me himself but sent me to the Arthritis Foundation. They began working on me at the stage of barely walking. I was in a pretty bad state. I was sent to therapy for treatment and given shots and medicines and taken care of as best they could.

But still I know they can't give me all the proper needs that I so desperately need without funds. If anyone knew the painful days and nights that we have lost of rest and just hoping there was someone that could take away the pain or just a new medicine or cure. That's not just one day or night but we have to live with this forever unless someone thinks of us as human beings and reaches out to help us. Please let there be someone, somewhere open their hearts to funds to help us. So that we, too, can have the help we need badly.

ELIZA M. BUERREMAN  
Defiance, Missouri

I am ninety-one years old and have been suffering from arthritis for a number of years. Many of my family and friends are suffering from the same crippling disease. Only those who have it can know how painful and crippling it can be. It strikes both old and young.

We plead for help!

Surely if our country can spend such huge sums on outer space, there should be something done for suffering here at home.







**HOLIDAY INN**  
**LITTLE ROCK, ARKANSAS**  
**November 12, 1975**





# TABLE OF CONTENTS

## CHRONOLOGICAL LIST OF WITNESSES LITTLE ROCK, ARKANSAS NOVEMBER 12, 1975

	<u>Page</u>
CAPLINGER, Kelsey J., M.D. President, Arkansas Chapter, Arthritis Foundation	3-420
BUMPERS, Senator Dale Arkansas, presented by Don Floyd, Arkansas Field Representative for Senator Bumpers	3-423
PRYOR, David Governor of the State of Arkansas	3-424
LIPSMEYER, Eleanor, M.D. Associate Professor, Department of Medicine, Rheumatology Section, University of Arkansas for Medical Sciences	3-426
SANDERS, Louis, M.D. Assistant Chief of Medicine, Little Rock Veterans' Administration Hospital	3-432
JACKSON, Carmault B., Jr., M.D. Trustee, American Society of Internal Medicine	3-434
WARNER, Roger J. Coordinator, Arkansas Regional Medical Program	3-442
DUNKLEY, Robert Parent of JRA Patient	3-449
HANISSIAN, Aram, M.D. Pediatric Rheumatologist, University of Tennessee, Center for Health Sciences	3-450
HUNTER, Dwight L., Jr. President, North Texas Chapter, Arthritis Foundation	3-454
FLETCHER, David King, M.D. Rheumatologist	3-455
SCHINDEL, William H., M.D. Rheumatologist	3-457

	<u>Page</u>
JACKSON, May, M.S.E., O.T.R. President, Arkansas Occupational Therapy Association	3-459
MORRIS, Dennis, R.P.T. Chief Physical Therapist, Arkansas Chapter, Arthritis Foundation	3-461
RAY, David B., Jr. Director, Department of Social and Rehabilitative Services, Arkansas, presented by Ted Newman	3-462
WILSON, T. E. III, M.D. Rheumatology and Internal Medicine	3-466
CLARK, Glenn, M.D. Former Chief of Rheumatology, University of Tennessee, College of Medicine	3-471
CAREY, Judith J. Patient	3-474
ROEBUCK, Ben E. Patient	3-477
CASH, Clarence Deputy Attorney General	3-479
CAPLINGER, Elizabeth Patient	3-483
TOWNES, Alexander S., M.D. Chairman, Medical and Scientific Committee, West Texas Chapter, Arthritis Foundation	3-485
TUNNELL, B. Travis, Jr., Ph.D. Clinical Psychologist, Arkansas Psychiatric Clinic	3-490
NELSON, Carl, M.D. Chairman, Department of Orthopedic Surgery, University of Arkansas, Campus for Medical Sciences	3-493
SATTERFIELD, W. W. President, Powell & Satterfield, Inc.	3-495

# SUBMITTED STATEMENTS

	<u>Page</u>
ANSLEY, Merle C., C.R.N.A. Little Rock, Arkansas	3-498
BARLOW, Delores, R.N. Jackson, Mississippi	3-498
BERRY, Arminta Little Rock, Arkansas	3-500
BOWKER, John H., M.D. Little Rock, Arkansas	3-500
BROWN, Sidney A. Little Rock, Arkansas	3-501
CORWIN, Mary Ellen Benton, Arkansas	3-502
DIDEN, Mary Elizabeth Pine Bluff, Arkansas	3-504
FRYE, Freda	3-505
HAZEL, Helen Little Rock, Arkansas	3-506
HERZOG, Kathleen Little Rock, Arkansas	3-506
HOOD, Pat Brookhaven, Mississippi	3-507
HUDSON, Bernice Little Rock, Arkansas	3-508
JAMES, Elizabeth E. Jonesboro, Arkansas	3-508
KINNAMOUTH, Eura	3-509
KIRKPATRICK, Billie, R.N. Magnolia, Arkansas	3-510
MONTGOMERY, Betty Cranston, R.N. McGehee, Arkansas	3-510



	<u>Page</u>
OGLESBY, Thelma A. Hope, Arkansas	3-511
OWENS, Virginia J.	3-512
RINGO, Walter Little Rock, Arkansas	3-514
SMITH, Relda	3-515
WILLIAMS, Mrs. Norman	3-515
FINCH, William C. Little Rock, Arkansas	3-516
KELTNER, Bill Little Rock, Arkansas	3-517
MASI, A. T., M.D. Memphis, Tennessee	3-518
ROSS, S. William, M.D. North Little Rock, Arkansas	3-521
SATTERFIELD, John V., M.D. Little Rock, Arkansas	3-522
SELLS, Robert K.	3-523
TAYLOR, Helen Little Rock, Arkansas	3-524
WALLACE, Lois	3-525
CLARDY, E. K., M.D. Hot Springs National Park, Arkansas	3-526
HUTCHESON, Fred A., M.D. Texarkana, Arkansas	3-529
NOTTINHAMPER, Dorothy Little Rock, Arkansas	3-529
PIRNIQUE, Allan S., M.D. El Dorado, Arkansas	3-530
THOMPSON, Mrs. Howell	3-531
FINCHER, Milton T., Jr.	3-532

	<u>Page</u>
FISER, Robert H., Jr., M.D. Little Rock, Arkansas	3-533
KETSCHER, Lottie Ruth Little Rock, Arkansas	3-534
LOWE, Betty, M.D.	3-534
ROBINSON, Ron Little Rock, Arkansas	3-535
TYSON, Eraday Meridian, Mississippi	3-537
HARRIS, Michael N., M.D. Little Rock, Arkansas	3-538
HONEA, Ross Little Rock, Arkansas	3-540
SMITH, Basil A.	3-541





P R O C E E D I N G S

FELTS: This is a meeting of the Arthritis Commission, established under Public Law 93-640, the Arthritis Act, charged with developing the National Plan to recommend to the Congress of the United States methods and details of implementation of mustering its resources in the task to combat arthritis. As you know, we are making a series of appearances around the country, listening to testimony, trying to obtain the feel from the people about their perception of these problems and their analysis of solutions to these problems in an effort to formulate our recommendations.

I am Dr. William Felts, a rheumatologist, Director of the Division of Rheumatology at the George Washington University in Washington, D.C., and am pinch-hitting this morning, along with Dr. Donaldson, for Dr. Engleman, who is the permanent chairman of this Commission, and who, unfortunately, had to return to California last night because of illness in his family. He asked that I express his regrets at not being able to be here today. I'm doubly pleased to be here as a native Arkansan and a graduate of the University of Arkansas School of Medicine.

I'll ask the other members of the panel, beginning with Dr. Donaldson on my left, to introduce themselves to you.

DONALDSON: I am Dr. William Donaldson. I am an orthopedic surgeon, and I practice in Pittsburgh, Pennsylvania.

LEWIS: I am Dr. Vivian Lewis, former university professor, from Wilberforce, Ohio.

GAY: I am Dr. William Gay, and I am, Associate Director of the National Institute of Allergy and Infectious Diseases at the National Institutes of Health, Bethesda, Maryland.

SHIELDS: I am Marlin Shields. I'm a physical therapist from Salt Lake City, Utah, and I'm representing the allied health professions on the Commission.

JENERICK: I am Dr. Howard Jenerick. I'm a physiologist and on the staff at the National Institute of General Medical Sciences at NIH.

MELICH: I am Doris Melich, President of the Utah Chapter of the Arthritis Foundation and a lay person on the Commission.

FELTS: Thank you. All persons appearing before the Commission will be required to clearly state their full name, title, organizational affiliation, and address. Witnesses appearing before the Commission are requested to provide a written statement of their remarks in order that their comments may appear in the official record of the meeting. Due to the number of persons who have requested to appear before the Commission, the amount of time will be limited to the presentations, and we request that you keep your presentation to approximately four minutes. This will enable us to have time to query you about certain aspects of it that we may wish to develop a little more fully. Should any witness exceed his allocated time, they may submit the written version of it, and it will be incorporated in the complete record of the meeting. We will usually ask a group of three or four individuals to come up to the table in front of us and proceed to take testimony by panel. Would Dr. Caplinger, Mr. Floyd, and Dr. Lipsmeyer come forward, please?

Dr. Caplinger, will you identify yourself and lead off, please?

TESTIMONY OF  
KELSEY J. CAPILINGER, M.D.  
PRESIDENT, ARKANSAS CHAPTER  
ARTHRITIS FOUNDATION

CAPLINGER: I am Dr. Kelsy J. Caplinger, President of the Arkansas Chapter of the Arthritis Foundation. My address is 8500 West Markin Street, Little Rock, Arkansas 77205.

On behalf of the Arkansas Chapter and the thousands of arthritics in Arkansas, I would like to welcome you here and thank you for selecting Little Rock as one of the hearing sites. We appreciate the opportunity to address the Commission and to present our views.

I am not a rheumatologist. I am here today because my wife has rheumatoid arthritis, and I know intimately its devastating effects on personal and family life. These effects may be pronounced even (as in our case) with early diagnosis, excellent care from the onset by a competent rheumatologist, and the immediate availability of orthopedic and physical therapy consultations. She has had a dozen operations, including some joint replacements. We have two small children. Fortunately, we have not had to cope with financial problems or geographical considerations. All these specialists are available within three miles of our home.

I have witnessed the effects of this disease through all this and have also observed the strong positive support offered through the Arkansas Chapter's Home Care Physical Therapy Program. The details of this program are outlined in Exhibit A attached to the written testimony previously submitted.

Briefly, the Home Care Physical Therapy Program was begun in 1965, and my wife was one of the first patients to participate. She was referred by

her rheumatologist to the Foundation's physical therapist for muscle and joint evaluation and recommendations. A program of physical therapy exercises was outlined in consultation with her physician. Follow-up was planned. Physician recommendations were reviewed, misconceptions corrected, and encouragement given. I know this has been helpful over the years.

Although in another medical specialty, I share some common problems with the rheumatologist and family physician who see most patients with rheumatoid arthritis:

- (1) The crush of a large number of patients to be seen.
- (2) The frightening numbers in the area who need to be seen.
- (3) The difficulty in getting good follow-up with some patients because of economic and/or geographic considerations.

The physical therapist in our Home Care Program is especially trained in the problems of rheumatoid arthritis and can make a significant addition to the total care of the rheumatoid arthritis patient. He is truly a "physician extender." He can enforce, educate, and supervise. He can decrease the need for some physician visits, especially in a static situation. This frees the physician to spend more time with patients who need his expertise.

Specifically, the physical therapist in the Home Care Program helps the patient by offering:

- (1) Encouragement more often than the physician can do. Many arthritics have emotional, financial, family, and logistical problems not readily apparent to a busy practitioner at infrequent office visits. No doubt our physical therapist does a good deal of "social work."
- (2) Home visits--Our physical therapist tries to make at least one home visit to patients who are severely affected and offer recommendations which can make the patient's life much easier. Let me give you an example that was helpful to us: A device to make a door--a lever may enable a patient with a hand problem to open a door and have free access to an area previously denied her. A simple thing--yet who thinks of it? It can make a great difference.
- (3) Simple things, like designing a ramp to eliminate steps on a porch and in split-level homes or four-inch blocks to elevate a favorite chair, can be greatly appreciated.

We have a self-help device technician who makes many of these items at less cost than they can be bought.

The doctor usually does not have time to personally explore the patient's daily environment and may not know of the self-help devices available. The Foundation has catalogs of self-help devices for patients



to help make them more independent and mobile. An example should help emphasize the importance of this:

My wife had used traction on the cervical spine in the past. Several years later symptoms recurred, and it was again recommended by her physician. Neither she nor I could recall how much weight should be used or for how long. Since she was enrolled in the Home Care Physical Therapy Program, a call to the physical therapist resulted in a home visit by him to set up the apparatus and advise about details. He provided a new type of head harness which was more comfortable and recommended a special pillow which was helpful. This service is not available anywhere at any cost.

Our chapter conducts hydro-therapy pool programs four nights weekly in heated pools at two Arkansas community hospitals in Little Rock and Fayetteville. The patients develop an interesting camaraderie at these sessions which is beneficial. The physical therapist can give them encouragement to increase joint mobility in the heated bouyant water. This is a popular and growing program among the patients.

The program of the Arkansas Chapter only scratches the surface. There have been 2,226 patients referred to the Home Care Physical Therapy program. It is estimated there are 36,000 patients in Arkansas with rheumatoid arthritis--many of whom would benefit from such a program. Through the National Arthritis Act, this service could be made available on a much larger scale through regional centers and local Arthritis Foundation chapters.

This program has several advantages.

- (1) Does not interfere with the doctor-patient relationship since patients must be referred. Patients have a choice of doctors, and reports after each visit are sent to the doctor.
- (2) It probably enhances the doctor-patient relationship since the therapist can enforce the doctor's recommendations.
- (3) It enables the follow-up to be in the patients' home area--they do not have to go to a large center for this specialized service. It decentralizes care and makes physical therapy more accessible.
- (4) It provides a method of data collection.

Continuing physician education regarding rheumatology and the referral services available are essential for this program to be successful. Any program of patient referral must originate with the local physician who sees the majority of arthritis patients in Arkansas. Continued education should be taken to them. We have held Consultation Clinics with a rheumatologist in various communities sponsored by a local physician. Thirty percent of Arkansas physicians have prescribed the home care program. The Home Care Physical Therapy program is effective and could be expanded under the National Arthritis Act. I am not minimizing the importance of research or the need for more rheumatology training

programs, but we should not neglect improvement of services to those already affected.

TESTIMONY OF  
THE HONORABLE DALE BUMPERS  
SENATOR FROM THE STATE OF ARKANSAS  
PRESENTED BY DCN FLOYD  
ARKANSAS FIELD REPRESENTATIVE  
FOR SENATOR BUMPERS

FLOYD: I appreciate this opportunity to present a statement before this Commission as you consider a long-range national arthritis program. As Governor of Arkansas and now as Arkansas' junior Senator, I have constantly advocated improved health care for all Arkansans--including expanded services for arthritics. I am quite sure that witnesses more expert than I in the care and treatment of arthritis will testify on specific needs in this field, and so, I would like to point out some of the advances made in health care in Arkansas during my two terms as Governor, which I feel have helped and will continue to improve health care for Arkansans.

As Arkansas' Governor, I recognized that one of the overriding problems in providing adequate health care was a lack of physicians in those rural areas of the State which most needed improvements in the availability and quality of health care. This was the case not only for individuals suffering from arthritis, but also for those needing medical care in general. As a result, one of the areas which received special attention during my four years as Governor was increasing the number of primary-care physicians throughout the State, especially in the sparsely populated areas that most needed them.

In order to increase the number of physicians available to treat those in need of medical care, one of my priorities as Governor of Arkansas was to expand the capabilities of the University of Arkansas Medical School to the point where it could accept 170 new students each year, rather than the present 120. From the fall term of 1970 to the 1974 fall term, the enrollment in the medical school's intern and residency program more than doubled from 162 in 1970 to 265 in 1974. In terms of training physicians to meet the needs of Arkansas, I think that expansions such as this will help keep our graduates in Arkansas and lower the physician-patient ratio in Arkansas to a more acceptable figure.

In 1973, the Arkansas General Assembly approved an expansion of Medicaid coverage to include prescription drugs. I believe that this was an important step in bridging a gap in the State's health care program and will prove to many Arkansans to be the difference between borderline health care and care that will enable them to recover much more rapidly. As the evidence proceeds to come in, I think it will be shown that this expansion of Arkansas' Medicaid coverage will have been a great step forward in our efforts to curb long-term debilitating effects of disease. It should be pointed out that this enlargement of Medicaid coverage will have a beneficial impact on those suffering from arthritis, but who cannot

afford to purchase the medicines necessary to relieve the pain and discomforts caused by arthritis.

During my tenure as Governor of Arkansas, an Emergency Medical Services (E.M.S.) program, funded with Federal grants, was begun, and it has helped bring medical care to thousands more Arkansans than had been possible before its introduction. The implementation of the E.M.S. programs in Arkansas has helped upgrade the quality of emergency medical care, and it will almost certainly continue to raise the quality of medical services in the State.

While I have primarily dwelled on health care in general terms, I think that these advances in the quality of Arkansas' health care programs have and will undoubtedly continue to have a positive impact on the care provided to arthritics and those suffering from related musculoskeletal diseases.

Again, I appreciate the opportunity to present this statement to the Commission, and I hope this hearing, along with those held in Milwaukee and St. Louis, will prove useful in the development of long-range arthritis policy. We appreciate your coming to Arkansas and hope you will call on us if we can ever assist you in the future. Thank you.

FELTS: Thank you, Mr. Floyd, and our thanks to Senator Bumpers for recognizing the effort of the Arthritis Commission and for presenting that review of the advances pertaining to health care within the State of Arkansas.

I would like to interrupt this panel presentation, if I may, and reconvene it at a later time and recognize at this time the Honorable David Pryor, Governor of the State of Arkansas, to enable him to address his busy schedule of the day.

TESTIMONY OF  
THE HONORABLE DAVID PRYOR  
GOVERNOR OF THE STATE OF ARKANSAS

PRYOR: Mr. Chairman, members of the Arthritis Commission, distinguished guests from out of State, fellow Arkansans, ladies, and gentlemen:

Let me thank you for inviting me here today, particularly for this opportunity to speak out and be counted among those concerned with the problem of arthritis.

As a present Governor and former Congressman, I am familiar with the problems of public health care and of the great expense to the public these plans can be.

But I am even more closely aware of the crippling realities of arthritis and related diseases, and when the two are put up against each other--public cost versus private suffering--I feel that no price is too



high, no expense too great, to work for the relief and care of those 20,000,000 Americans needing our help today.

Let me commend your organization for taking this active role in defining an "Arthritis Plan" on a national level.

This is the kind of citizen participation that all forms of government need in 1975.

We are aware of the importance of long-range projections and the dangers of attempting to solve problems on a haphazard basis.

Fortunately, the Congress saw fit in January to devise a plan in the National Arthritis Act, and in the course of hearings and testimony I am sure that Congressional committees will receive the best professional opinion on the subject.

I am delighted to see that they will receive as well the considered and expert testimony of private individuals.

In looking at the needs of Arkansas, the Congress will find that we have over 1500 rheumatoid arthritics in the State, served by more than 15 therapy clinics.

In addition, some 2400 attend regular hydrotherapy sessions in Little Rock and Fayetteville, with another 2000 being assisted by equipment on loan from the Arkansas Chapter of the National Arthritis Foundation.

In 1974, nearly \$200,000 was spent fighting arthritis in Arkansas.

And we have among the most effective and dedicated chapters anywhere in the country.

I know of no greater need in the State than our participation in Federal plans and projects to relieve the ravages of this disease.

Although arthritis recognizes no age limit or barrier, the elderly citizens of Arkansas are particularly affected and stand to gain immediate relief from Federal programs.

We are basically a rural State, with only 17 of our 75 counties considered urban.

At the same time, more than 77 percent of our elderly population live in rural areas while, on the other hand, 65 percent of all licensed physicians reside in eight urban counties.

The requirements of the elderly in receiving adequate, and particularly emergency, medical care are dramatically illustrated in these figures.

I have close knowledge and awareness of elderly needs in the State, and I hope that these citizens, many of them afflicted with arthritis, will not be forgotten in the plan that is now being written.

I deeply appreciate this invitation and look forward to the findings of the Commission in taking testimony from the five states in our region.

FELTS: Thank you very much, Governor Pryor. On behalf of the Commission I would like to thank you for taking time from your busy schedule to appear here this morning. I would like to thank you on behalf of at least 20 million Americans suffering from arthritis for your ongoing efforts to coordinate and achieve improvements in health care. Thank you very much.

If our panelists will reconvene--Dr. Lipsmeyer, please.

TESTIMONY OF  
ELEANOR LIPSMeyer, M.D.  
ASSOCIATE PROFESSOR  
DEPARTMENT OF MEDICINE, RHEUMATOLOGY SECTION  
UNIVERSITY OF ARKANSAS FOR MEDICAL SCIENCES

LIPSMeyer: I'm Eleanor Lipsmeyer. I'm a rheumatologist. I'm an associate professor at the University of Arkansas Medical Center in the Section of Rheumatology there.

The needs of the arthritic patient in this State and Nation are many and varied. They include:

- (1) Need for dissemination of current techniques of care to the primary care physician who treats the patient in the community. This includes information about both newer drugs, as they become available, and improved physical measures, as they are developed.
- (2) Need for several additional rheumatologists in Arkansas to diagnose and care for the complications that may arise in the course of arthritis or related diseases.
- (3) Need for physicians interested in juvenile rheumatoid arthritis and other joint diseases seen in children.
- (4) Need for more efficient use of present physical therapy resources, and extension of these resources into areas of the State where they are not presently available.
- (5) Need for funds committed both to basic research into the cause of and cure for arthritis and to clinical research into improved drug and rehabilitative modalities.

Primary care physicians care for the majority of the nearly 120,000 patients with arthritis in the State of Arkansas. To help them with this task, the Arthritis Foundation, Arkansas Chapter, with the financial support of the Regional Medical Program, administers a program of continuing medical education. In the last 18 months, physicians throughout Arkansas have attended lectures and discussions centered on newer concepts of patient care. Visiting rheumatologists have seen many arthritic patients in consultation clinics, presented new classifications

of disease, and discussed modifications of drug and rehabilitative therapy. Since practicing physicians carry a heavy load in our State, aiding them in updating their concepts of rheumatic disease facilitates their continued education and benefits the arthritic patient under their care. Upon cessation of the Regional Medical Program, scheduled for June 1976, new monies to continue this professional education program will be urgently needed.

Many obscure forms of arthritis (e.g., ankylosing spondylitis, Reiter's syndrome, and psoriatic arthritis) defy diagnosis or definition, and expert knowledge is necessary for the initiation and direction of therapy. The complications of collagen vascular diseases, rheumatoid arthritis, systemic lupus erythematosus, progressive systemic sclerosis, and polymyositis are complex and potentially lethal. These diseases, when they become systemic and progressive usually demand the intervention of an internist or rheumatologist. Currently, there are five rheumatologists in the State. It is impossible for them to see all patients with these complications. Funds for a training program in rheumatology are urgently needed at the University of Arkansas for Medical Sciences so that the patient whose condition demands the care of a rheumatologist may find one available in his area. Our current program in the university system extends teaching to sophomore, junior, and senior medical students. House officers in family practice and internal medicine participate in the rheumatology clinics at the university and Little Rock Veterans' Administration hospitals. There is no provision for fellowships in rheumatology, chiefly because of lack of funds. Incorporation of fellows into the teaching program would necessitate an increase in the medical faculty at the UAMS and VA, further development of ambulatory care facilities to accommodate fellows as well as house staff, and allocation of rheumatology fellowship training funds.

There is, at present, no physician in the State with training in the treatment of juvenile arthritis. The Arthritis Foundation, in cooperation with Arkansas Children's Hospital, the Pediatric Department of the University of Arkansas for Medical Sciences, and the Regional Medical Program, is sponsoring a training period to enable pediatricians to become proficient in the care of these children. However, as in all cases of arthritis, the disease is best treated within the community, by a physician who is readily accessible, with facilities for physical therapy manned by competent therapists who have a close working relationship with the patient and the physician.

Although drug therapy is necessary, physical measures also play a role to insure that the patient will receive the optimum in physical and rehabilitative medicine. The Arthritis Foundation has developed a home care program which incorporates home visits by the physical therapist into the total care of the arthritic. Study of the patient's home environment by a therapist, although time-consuming, allows the maximum return in mobility and productivity through cooperation of the therapist and patient.

Currently, physical therapy in association with hydrotherapy has been made available to patients with arthritis by the Arthritis Foundation at local hospital pools in Little Rock and Fayetteville. This form of



therapy is quite beneficial, and without it many arthritics would lose joint motion. Funds for maintenance of this form of therapy should be made available to insure continuation of currently operating programs and to open "pool programs" in other areas of the State. Night-time operation of pools which usually are idle during this time provides more efficient use of equipment.

Research into the basic mechanisms which produce arthritis must be continued. It is unlikely that a cure will be forthcoming until the cause is known. To date, basic laboratory research into rheumatoid arthritis has delineated many immune phenomena which now serve as a basis for our understanding of immunology and hypersensitivity. The concept of autoantibody formation in rheumatoid arthritis and systemic lupus erythematosus has been demonstrated by this research, and lymphocyte function in these diseases has recently been defined. But this is not enough. The etiologic agent remains elusive, and, until it is known, curative measures cannot be defined. Until we have this information, clinical research must continue to evolve new therapeutic regimens and new physical measures to provide relief for the patient until the cure for arthritis is found.

FELTS: Thank you, Dr. Lipsmeyer. Do members of the Commission have any questions? Dr. Donaldson.

DONALDSON: Dr. Lipsmeyer, you refer to certain needs if the university were, in fact, to have a comprehensive center. Would you give us a little better idea of manpower needs, money needs that would be required to convert your unit into what you would consider a basic overall comprehensive unit?

LIPSMEYER: I can't give you any exact figures, sir. To convert our unit, we would probably have to have one more faculty member; at the VA, they would probably require another faculty member. We would have to have training funds for rheumatology fellows, and we would have to have commitment of more room to see patients by the university administration. Right now we run a clinic on Tuesday and Friday, and we have about three students at a time. We have two interns, two residents in the clinic, and that's about all the space that we can have at this time. To incorporate fellows we'd have to have a commitment of more space at least to see outpatients.

DONALDSON: How many are on your staff now? Rheumatologists, that is?

LIPSMEYER: I'm the only one.

DONALDSON: You're the only one?

LIPSMEYER: And, Dr. Sanders is the only one at the VA.

DONALDSON: So, what you're asking for as a basic unit would be to really double your staff?

LIPSMEYER: Yes, sir.

DONALDSON: And with the idea that you would take one fellow per year, or something like that?

LIPSMEYER: Probably, at the beginning, one fellow per year for a two-year fellowship.

DONALDSON: You have the facilities to run a research program?

LIPSMEYER: Yes, sir. I have a research lab of my own, and there's enough room there to extend this to a fellow.

SHIELDS: Regarding your Home Physical Therapy Program; if 30 percent, then, of the primary care doctors are using the services, and if you have used this service mainly to try to help them do a better job at the primary care level, has there been any resentment, or what are the feelings of the primary care doctor for this service?

VOICE: Well, the patient has to be referred by their doctor to the program. We see our job as educating them to the services we have available and working with them in any way that we can. Most doctors really don't know what to recommend, and the usual recommendation is, "Will you please evaluate Mrs. Jones and make some recommendations and outline a program?" And it works very well. We really have no animosity with the local physicians.

LIPSMEYER: I think that one of the best helps with this program has been the visits of rheumatologists throughout the State in this continuing education program that we have had going on. Since that time, we have had an increase in referrals and new referrals from physicians who knew nothing about it, and since we have been telling them about rheumatoid arthritis and about the things that can be done through this program, I think that we have extended it fairly greatly. The physicians are quite devoted to the program, and they feel no resentment at all; they are quite enthusiastic about it.

DONALDSON: They are very grateful for the help, probably.

LIPSMEYER: Yes, sir, they are.

VOICE: Do you feel at this time that you are reaching the rural areas much better than before, or is the emphasis primarily on the city?

LIPSMEYER: For physical therapy or teaching, ma'am?

VOICE: Teaching, or whatever programs you may have.

LIPSMEYER: The teaching programs are extended to rural areas. Now, we do go to places such as Eldorado and Pine Bluff, but most of the places where we are going for continuing education are out in the rural areas. Since that time we have had better referrals from the rural areas. Previously, they had been somewhat to the urban areas. We have one physical therapist who goes out through the State, but recently we have contracted out some of the physical therapy to separate areas around the

State, and this has been helpful too, since one therapist has difficulty in covering the whole State.

DONALDSON: Your RMP program with the Arthritis Foundation is what--about a year old at the present time?

LIPSMEYER: This is the second year. It started in July of '74.

DONALDSON: But as a functional unit, it is about a year old--it took you a while to get started?

LIPSMEYER: Yes, sir.

DONALDSON: And during that time, how many physicians do you feel you have contacted and provided continuing education?

LIPSMEYER: I'm sorry, I don't know the numbers. They are known by the Arthritis Foundation. I would probably say from 75 to 100.

VOICE: I think the number is in that range, and I'm sorry I do not know the exact one. Also, we have had contact, with the seminars, with the physical therapists, nurses, and other paramedical personnel in the communities. For instance, a seminar being held Harrison, Arkansas, would be open to (depending on the wishes of the local physician) the other paramedical personnel there. So we feel that we not only reach the physicians in the outlying areas, but we also reach others who can be of help to patients.

FELTS: Dr. Lipsmeyer, I did not quite understand from your presentation your impression of the core curricula of the medical school here, relating to rheumatology. How much exposure are the medical students getting to this problem?

LIPSMEYER: I think that since I've returned, we've increased it a great deal. In their sophomore year, I teach part of the basic immunology, and there is an emphasis on autoimmune disease and mechanisms. Then when they have physical diagnosis in the sophomore year, Dr. Sanders and I teach them about physical diagnosis and physical examinations from a rheumatologic standpoint. Now this wasn't done until about six years ago. Now we have--rounding with juniors, we see rheumatologic problems. The seniors elect to come on to the service, and so we essentially train from three to six seniors at a time for a six-week period. So, I would say that we are probably reaching half the class that way. I think that where we are making the biggest headway is in training the house staff--the family practice and the internal medicine house staff--in rheumatologic methods and treatments before they go out into practice.

FELTS: In some of the previous presentations this panel has heard in other cities, there have been some assessments of the curricular programs to the effect that they are weighted in many regards, or overweighted, so that there is rheumatologic underexposure in comparison to the patient need when one is confronted with it when he gets into practice, and in comparison to some of the other categorical teaching areas. What is your assessment of your program here in that regard?



LIPSMEYER: Well, if you measure it against how many faculty members there are for each department, cardiology would be terribly overweighted compared to rheumatology, and that sort of thing. The staff at the university is not terribly big, and so, if there were another staff member in rheumatology, I think that it would probably be equal to gastroenterology or to pulmonary medicine or something like that. It isn't as big a program, say, as cardiology or hematology.

FELTS: Do I also gather from your presentation that in order to achieve any expansion that patient care cannot be counted upon to generate enough funds to allow such an expansion, and that you don't foresee economic resources from any other source? I'm not trying to put words in your mouth.

LIPSMEYER: I don't see economic resources from any other source. As to whether enough patient monies could be generated to support an extra faculty member or to support a training program-I don't see at this time that that would be feasible, that we could generate that much money.

FELTS: Any other questions?

VOICE: Would that be your priority, then, if you had a choice as to where we should spend our money--in training of new rheumatologists?

LIPSMEYER: I won't be so categorical as to say training new rheumatologists. I think that one of the biggest lacks is in the continuing education out in the State in physicians who are already trained, because most of the rheumatologic techniques and ideas have been developed since these fellows were out of school. So, a lot of the training, I think, should go into continuing education, into the people who are out already. I think that, especially in Arkansas, we need more rheumatologists, but I think that we have to put some money into continuing education to tell the physicians who are out there what else they can do to relieve pain of the arthritic patient.

FELTS: I'd like to thank these panelists very much--Dr. Caplinger, Dr. Lipsmeyer, and Mr. Floyd, who had to depart. We appreciate your testimony very much.

Would Dr. Sanders, Dr. Jackson, and Mr. Warner come forward, please? Dr. Sanders, would you make your presentation, please?

TESTIMONY OF  
LOUIS SANDERS, M.D.  
ASSISTANT CHIEF OF MEDICINE  
LITTLE ROCK VETERANS' ADMINISTRATION HOSPITAL

SANDERS: I'm Louis Sanders. I'm a rheumatologist, and I'm the Assistant Chief of Medicine at the Little Rock Veterans' Administration Hospital. I'm also the Chairman of the Medical and Scientific Committee of the Arkansas Chapter of the Arthritis Foundation.

The diagnosis and treatment of arthritis in an essentially rural State such as Arkansas presents problems somewhat different from those found in many other areas of the country. First of all, as you have already heard, Arkansas has a very small number of physicians who are rheumatologists. In the 1974-75 membership directory of the American Rheumatism Association there are only ten members of the association listed for the entire State, and of these less than half are practicing rheumatologists who engage in seeing patients. Since we have well over 100,000 arthritics in the State of Arkansas, obviously very few of these have access to a practicing rheumatologist. A fair number of these patients do have problems that require some expertise in diagnosis and treatment, thus I think a crucial need for our State is more clinical rheumatologists. As Dr. Lipsmeyer pointed out, at the present time there is no clinical rheumatology training program at the University of Arkansas Medical Center, and, therefore, we are dependent--if we are going to get more rheumatologists--on rheumatologists trained elsewhere. Because of the nationwide demand for such individuals, the likelihood of attracting such people to the State of Arkansas is rather slim. At the VA Hospital we've been trying for two years to recruit another rheumatologist and have been unable to do so. Therefore, I think one crucial need from our standpoint is the establishment of clinical rheumatology training programs in various areas throughout the country. I would emphasize clinical rheumatology in contrast to the usual rheumatology fellowship which emphasizes research to a large degree. Basic research is important and certainly is needed. However, most of the currently available rheumatology training programs really do little more than train academic rheumatologists which are in tremendous demand throughout the country, the demand cannot be filled. We do not have at the University of Arkansas Medical Center and the Little Rock VA Hospital facilities large enough or strong enough to support this type of basic and clinical training at the present time. However, with very little personnel investment I think that we could train one or two individuals in clinical rheumatology. Now, I would suggest the same situation probably exists in many other institutions which are not currently capable of being arthritis centers as such. Therefore, I would urge the establishment of a nationwide training program for clinical rheumatology to include smaller institutions which are not actual arthritis centers as such, but where competent clinical rheumatologists do exist to provide such training.

Such a program will help only in the long run. For the immediate future, I think that one of the primary needs, certainly for our State, is programs of education for the currently practicing physicians to make them more knowledgeable in diagnosis and treatment of arthritis. Dr. Lipsmeyer and Dr. Caplinger have already described the program that we have here in



Arkansas. I think it is functioning in a very satisfactory fashion; at the present time we have reached 121 unduplicated physicians through this program. Continuation of and expansion of this program that has been begun with the help of the Arkansas Regional Medical Program, I think, is essential for the education of the physicians in the State of Arkansas.

In the area of patient care, we do feel very strongly that physical therapy conducted on a day-to-day basis by the patient in his home is the answer to prevention of crippling in the great majority of patients with rheumatoid arthritis. For this reason, we feel that our home-based physical therapy program is an essential part of the treatment of the patient. This program has been described previously and I will not reduplicate that, except to say that I think that if we are reaching a third of the doctors in the State, that means that we are not reaching two thirds of them, and therefore a significant number of patients of these physicians are not being made available of this service.

Hydrotherapy is another important modality in the treatment of rheumatoid arthritis. We do have currently two pool programs available in Arkansas--one in Fayetteville and one in Little Rock. I think that the benefits of these programs to the patients are inestimable. In addition to the actual medical benefits that the hydrotherapy itself produces, these programs are valuable to the patient in providing a type of group therapy and camaraderie which has marked additional benefits. It's true that therapeutic pools are not now available in other hospitals throughout the state. I think the provision of such facilities in future constructions should be considered and that perhaps the use of local heated motel or YMCA pools on a night-time basis would make it possible to expand this program.

One of the absolute needs to institute such a program is adequate numbers of and well-trained physical therapists to conduct it. Such a program would be useless without the proper personnel to run it. The Arkansas Chapter of the Arthritis Foundation is currently participating in the training of physical therapists in cooperation with the School of Physical Therapy at the State College of Arkansas. In this program, one of their physical therapists spends some time with our Foundation physical therapist in his home care program. I think it is extremely important to train as many physical therapists as possible in the special needs and care of the arthritic patient so that we can improve the expertise of the graduates of our physical therapy school. In addition, we will be shortly undertaking a cooperative effort with the Physical Therapy School at Wichita, Kansas, to provide training of one of their therapists in the home care program. I think that with further funding this type of program could be expanded and provide additional expertise for a larger number of physical therapists. I think it should be expanded to provide such training for all graduates of our physical therapy school.

I think that with the proper combination of physical education, increased production of clinical rheumatologists, home-based physical therapy, hydrotherapy, and the proper use of the drugs currently available, much can be done to alleviate the suffering of the patient with rheumatoid arthritis now, while we look forward to that golden day when the cause is discovered and the cure produced. Thank you.



FELTS: Thank you, Dr. Sanders. Dr. Jackson.

TESTIMONY OF  
CARMAULT B. JACKSON, JR., M.D.  
TRUSTEE, AMERICAN SOCIETY  
OF INTERNAL MEDICINE

JACKSON: I am Carmault B. Jackson, Jr., a practicing internist in San Antonio, Texas, and a trustee of the American Society of Internal Medicine, whose Executive Committee has reviewed and approved this testimony. ASIM is a federation of 51 component societies of internal medicine. It has more than 14,000 members who, by training and practice standards, are recognized as specialists in internal medicine. Most are private practicing internists delivering primary care, subspecialty care, or both.

Public Law 93-640 in its findings and declaration of purpose cites a need for a national "Arthritis Plan," "Arthritis Coordinating Committee," "Arthritis Screening, Detection, Prevention and Referral Demonstration Projects," a "National Data Bank," as well as creation of "Comprehensive Arthritis Centers." Further, it implies that epidemiological studies will create a "great potential for making major advances."

ASIM is aware of the prevalence of rheumatic disorders, their commonality to the practices of its members, and the limited effectiveness of therapies available. The partial as well as the total disabilities caused by these diseases unquestionably represent great cost in suffering and dollar loss, direct and indirect. Therefore, ASIM concurs with the spirit and goals of PL 93-640. However, we also have a few concerns about the methods proposed to approach those goals. Well-intentioned decisions could have counterproductive results. Therefore, we respectfully request that the Commission assess these considerations in its deliberations.

First, although the Federal Government has repeatedly elected to subsidize a categorical approach to certain diseases, there are obvious limitations to such efforts. In some instances inequities of benefits to patients have resulted, and ASIM believes that legislation and regulations should endeavor to prevent such disparities unless exceptional justifications prevail.

Secondly, ASIM is aware that significant doubts exist in the minds of many clinicians and other informed citizens as to the definition and intended function of "Centers." Some regard these as high-cost, low-output, vested-interest institutions with limited ability to provide total continuity care capable of meeting the multiple needs of significant numbers of patients. Further, they may contribute significantly to the rising costs of health care without apparent proportionate benefits. While this view probably is exaggerated, it has enough advocates for ASIM to recommend deliberate caution in establishing "Centers" and to plead for concise definitions to minimize over-expectation on the part of the public and antipathy of a significant segment of the medical profession. We further urge that regional need and desire be a part of planning, and that a requisite for any institutions designated as "Centers" be to demonstrate

a plan acceptable to its medical community that allows the patient's primary physician to participate in a mutually acceptable manner with his patient while relating to a "Center" experience.

Thirdly, ASIM believes that further emphasis in rheumatology training deserves high priority consideration by the Commission. It appears that core curricula of many of the medical schools are deficient in exposing students to adequate experiences in diagnosing and managing rheumatic diseases. Additionally, continuing education courses for internists reflect a recognized need by practicing clinicians for updating their knowledge in this field.

Lastly, and of major concern to ASIM is Section 438 (c) (1) which states, "As soon as practicable after the date of enactment of this section the Secretary, through the Assistant Secretary for Health, shall establish the Arthritis Screening and Detection Data Bank for the collection, storage, analysis, retrieval and dissemination of data useful in the screening, prevention, and early detection involving patient populations with asymptomatic and symptomatic types of arthritis, including where possible, data involving general populations for the purpose of detection of individuals with a risk of developing arthritis." Although the American Society of Internal Medicine sees potential value in total clinical data, inter-institutional cooperation, and research, we have major concerns regarding confidentiality, validation of data, and demonstrations of cost/benefit feasibility. We believe these should be addressed in depth through expanded research prior to attempting to implement a "National data system."

It might be useful to note that the Socio-Economic-Research and Education Foundation (SEREF) of ASIM partially funded the American Rheumatism Association's Medical Information System (ARAMIS) early in its development. Internists are interested in data systems, expanded clinical applications, and their proper development. While we regard ARAMIS as an exciting approach to data selection, storage, and manipulation, we also believe that it must be extended to a limited number of other institutions and personnel; subjected to strict validation requirements; demonstrate significant epidemiological, clinical research, educational, and other attributes; and also provide assurance of a reasonable level of professional acceptance and utilization before it is qualified to become the basis for an operational, substantial, federalized data system.

ASIM is very concerned about the issue of confidentiality. The proposed data bank could accumulate personal information with individual patient identity on a potential of up to 20 million Americans. The Right to Privacy Act may prove to be inadequate protection for such patients. A large segment of the public has not yet identified this issue or its potentially serious ramifications.

For your information and review we have attached one report of the ASIM Board of Trustees relating to some of the problems of confidentiality. Summarily:

Concerns relating to the confidentiality of medical records are increasing as involvement of third parties in health care delivery has

expanded. These concerns are heightened by poorly defined authorizations for release of information and by the increasing capability of machines for communicating interrelated identifiable patient information without the patient's knowledge and approval.

The right of the patient to confidentiality of his medical records is irrevocable. Confidentiality is a privilege which belongs to the data subject. Third parties seeking any exceptions should be charged with responsibility of fully informing patients of the possible consequences of such exceptions, and use by third parties of any privileged information must be limited to the purpose for which it was solicited.

Current laws do not adequately protect the patient's rights. The ASIM believes that there is immediate need for legislation which protects personal data on individual citizens and groups of citizens. We believe that there is a potential for personal injury or abuse by "authorized users."

Release of information must be with the patient's consent and must include a signed statement that is current, timely, and consists of the following components:

- (a) A statement of purpose or need for such disclosure.
- (b) The name of persons or organizations to whom disclosure is to be made.
- (c) A description of a specific type or types of information to be disclosed.

ASIM acknowledges a need for long period study of patterns of disease. While data bank potentials are exciting, we also view them as unproven. Experiments of the ARAMIS type may be oversold before they are thoroughly evaluated, and subsequent shortcomings or failures could become detrimental factors to alternative approaches toward the same goal(s). It also is possible that such a data bank may fail to meet proposed guidelines being developed by the National Bureau of Standards. Therefore, we urge that the Commission recommend that any data system be research oriented, that variable approaches be attempted, and that all such efforts be critically evaluated regarding usefulness compared with cost.

Thank you very much for the opportunity of appearing before you. I hope these views will be helpful in your deliberations. I will be pleased to attempt to answer any questions you may pose.



APPENDIX SUBMITTED BY  
CARMAULT B. JACKSON, M.D.

February, 1975

Board of Trustees Report C

Reference Committee E

To the House of Delegates

SUBJECT: Confidentiality

For the past two years, the ASIM Board of Trustees has been concerned with the problem of invasions of an individual's privacy resulting in disclosures of confidential information.

Although such disclosures can relate to all kinds of personal data, ASIM's efforts have been largely directed to a definition of the problem in relation to medical records.

I. History of ASIM Actions

- A. In November 1973, the Board of Trustees approved the following statement on confidentiality of medical records:

Background

Concerns relating to the confidentiality of medical records are increasing as the involvement of third parties in health care delivery is expanded. These concerns are heightened by poorly defined authorizations for release of information and by the increasing capability of machines for communicating interrelated identifiable patient information without the patient's knowledge and approval.

Evaluation

The right of the patient to confidentiality of his medical records is irrevocable. Third parties seeking any exception should be charged with the responsibility of fully informing patients of the possible consequences of such exceptions, and use by third parties of any privileged information must be limited to the purpose for which it was solicited.

Current laws do not adequately protect a patient's rights. The American Society of Internal Medicine believes that there is an immediate need for legislation which protects personal data on individual citizens and groups of citizens. We believe that there is a potential for personal injury or abuse by "authorized users."

Policy statement

The American Society of Internal Medicine will work through the appropriate legislative channels and appropriate professional organizations for a law which will provide due process guarantees. These guarantees of confidentiality are to include security, accuracy, provision for change, knowledge of purpose, and informed permission for use.

- B. In a second action, the Board of Trustees sent a letter to identified insurance company medical directors concerning the 1974 House of Delegates resolution No. 4: "Confidentiality."

"Dear Doctor: In May of 1974, the House of Delegates of the American Society of Internal Medicine adopted a resolution expressing its opposition to using any commercial data gathering organization to collect, assemble or have access to privileged information. Our members regard it to be highly improper for privileged information to be provided to acknowledged credit reporting agencies. We have doubts that most patients signing release of information authorization are really informed as to the complete use and potential misuse of such information.

"Although your company may not employ such an organization, we would welcome your opinions on this issue in that they may be of assistance in determining subsequent action by the American Society of Internal Medicine.

Sincerely yours,

Glenn Molyneaux, M.D."

This letter has resulted in multiple responses which have been passed on to the appropriate ASIM Committee for action.

- C. In a third statement, the Board of Trustees approved a Health Care Technology Committee proposal from the Research and Development Council regarding "the committee's interest in data management aspects of PSRO's." The resolution reads as follows:

#### Data Control by Government Programs

##### Background

There is a history of physician difficulty in obtaining data aggregated by government programs.

##### Evaluation

The government is increasingly involved in information gathering and there seems to be a natural tendency by those who pay for data to exercise total ownership prohibiting reasonable and necessary access. We are concerned about

access to information generated in the process of medical care. We believe that access to data from federal programs must be provided in order that the data itself may be subjected to scrutiny regarding necessity, appropriateness and quality.

### Policy

The American Society of Internal Medicine believes that the right of access to data by a data subject, either an individual or an organization, is irrevocable.

- D. In additional action, the Executive Committee and the Board of Trustees are maintaining close contact with the AMA and the pertinent proposals from its Legislative Department, including one to establish a privacy protection commission which reports to the Council on Medical Service. ASIM concurrently monitors proposals such as HR-17323, sponsored by Representative Kemp of New York, which proposes the establishment of "a Federal Medical Privacy Board with responsibility for promoting protection of the right of privacy as it relates to personal medical information."

## II. Current Principles

- A. The ASIM Board of Trustees has been concerned, prompted partly by PSRO activities, with federally developed data collection criteria and model systems. The principles which the Board feels must be protected are:
  - 1. Confidentiality is a privilege that belongs to the data subject.
  - 2. The (state and federal) "government" may require disclosure only for the purposes of an "act" (law).
  - 3. Release of information must be with the patient's consent and must include a signed statement that is current or timely and consists of the following components:
    - a. A statement of purpose or need for such disclosures.
    - b. The name of persons or organizations to whom disclosure is to be made.
    - c. A description of the specific type or types of information to be disclosed.
- B. Presently, several groups (notably the American Civil Liberties Union) are making different attempts to offer definitions of the content of medical records and to establish a hierarchy of access. Confusion derives from



different groups using multiple definitions such as "active record," "working record," "primary record," "privileged record," "permanent record," "secondary record," and "tertiary record." Many of these proposals suggest a system of dual record keeping.

An example of the complexity of this problem is contained in the following quotation on dual record keeping extracted from a committee report of the American Civil Liberties Union "A Revised Proposed Policy on Privacy of Medical Records":

- "1a. Medical records for these purposes are any materials relating to a person's physical or mental health prepared for retention in permanent form in the possession of any custodian of medical records. The term does not include notes made and retained by a physician solely for his personal use, or notes of information given to a physician in confidence by a third person in connection with diagnosis or treatment of a patient, unless such notes are used to affect the patient's rights or benefits or liabilities in which case their use is subject to due process requirements.
- b. Any person may, on request, have access to and the right to have copies of his own medical records in the possession of his doctor, a hospital, or any other custodian of medical records. A physician who treats or examines a person may apply to a court to be relieved of his obligation to give the patient access and the court may grant relief only if it is satisfied in an adversary hearing that the disclosing of the record to that patient would be severely damaging to him in such a way, for example, as to threaten his life or that of another person. This court action may not be available to a hospital after a patient has been discharged nor to any custodian of medical records not actually engaged in providing health care to the patient.

In a footnote to those definitions, the following is identified "the committee contemplates that these definitions and the proposed policy would encourage a dual system of medical record keeping, and regards this as a desirable outcome. Rather than deny a patient the right to see and copy his own records because they contain personal comments, confidential, or embarrassing material of any kind, the committee proposes that medical practitioners should keep any such notes, if they keep them, exclusively in their own possession for their own private use."

Under another footnote

"The permanent records will still be subject to applicable criteria for sufficiency that apply in any good practice of medicine, and therefore, should contain all information needed for purposes of diagnosis and treatment of the patient and maintaining an adequate medical history for future use."

In response, we have written a position paper with definitions which identifies and attempts to resolve some of the current confusion.

### III. Proposed Policy

The following ASIM policy is offered:

#### A. Definitions

1. The primary or permanent record belongs to the physician and his patient. It is the permanent data base which meets peer requirements for sufficiency and its release should not occur except with dual consent and then only for the purpose of treatment or patient management. The single exception to this consent requirement is the instance of legal action in which case record usage requires due process guarantees. The Primary Record may not contain notes made and retained by the physician solely for his personal use.
2. The active (working) record is the property of a physician and is solely for his personal use in connection with the diagnosis or treatment of a patient and is privileged unless such privileges are used to affect the patient's rights, benefits or liabilities, in which case its use is subject to due process requirements. The active record may contain notes which the physician intended solely for his own use.
3. Secondary data should be released only in a minimum set of data elements which will fulfill a "demonstrated need," and then only with the authorization of the data subject(s).
4. Certain secondary records used in audit or peer review should be privileged and prohibited from being admitted in court proceedings.

#### B. Life Span

1. The life span of an adult's permanent record should be no less than five years from the date of last activity (data entry) unless surgery has been performed. In this instance, it should be kept for at least ten years

unless the patient dies. The record should be maintained for a period of (at least) two years after death.

2. The minor's permanent record should be maintained for at least five years after reaching adulthood. If surgery has been performed on a minor, the record should be preserved for a minimum of ten years after the patient becomes an adult under state law.
3. Primary medical records for mentally incompetent persons should be maintained throughout the individual's lifetime without regard to activity since statutory limitation may never prohibit suit for alleged malpractice.
4. The life span of a secondary record with patient identity should correspond exactly to the period required to accomplish specific objectives for which it was obtained.

FELTS: Thank you very much Dr. Jackson. Mr. Warner.

TESTIMONY OF  
ROGER J. WARNER  
COORDINATOR, ARKANSAS  
REGIONAL MEDICAL PROGRAM

The Arkansas Regional Medical Program awarded a \$100,000 grant to the Arkansas Chapter of the Arthritis Foundation to implement a statewide program combating arthritis in this State. This grant became effective in August 1974, with implementation of the program underway in September 1974. The success of this activity, and the enthusiasm with which the project was undertaken by the Foundation, resulted in approval for a second year of funding beginning in July 1975. It was, in fact, rated as the "number one priority" for funding by the Regional Advisory Group; the 60-member group that sets the policy and makes funding decisions for the Regional Medical Program in Arkansas.

The first year's grant period has been completed; and data is available. The major emphasis during that period focused on reaching as many arthritic patients as possible, particularly those patients who had not previously received treatment. A major portion of the attack was to develop consultation services and provide information for practicing physicians throughout the State: to inform them of available services as well as to increase the physicians' expertise in handling arthritic patients. Implementation of the project's objective aimed at taking the program out to the local physicians, rather than having a highly specialized program at one location and bringing the physicians in, has been markedly successful. During the first year of the activity the project had a series of three rheumatology consultation clinics at each of the following locations: Fayetteville, Harrison, Jonesboro, Monticello, Camden, El Dorado, Texarkana, and Batesville. Two physicians, Dr. Eleanor



Lipsmeyer of the University of Arkansas for Medical Sciences, and Dr. Lewis L. Sanders of the University of Arkansas for Medical Sciences and the Veterans Administration Hospital at Little Rock, served as visiting rheumatologists. Two hundred and ten physicians, physicians-in-training, and dentists, along with 230 allied health personnel, attended these conferences. Twenty-one patients were seen as part of the demonstration programs at the clinics. It is interesting to note that 65 of the physicians attending the consultation clinics had not, at that time, been referring patients to the Arthritis Foundation's Home Care Physical Therapy Program; eight of the 65 now refer patients.

A specialty consultation clinic on juvenile rheumatoid arthritis, utilizing three out-of-state consultants, was held at Childrens' Hospital in Little Rock. Fifty-five physicians, physicians-in-training, and allied health personnel attended this clinic. The following day, a seminar was held for the Arkansas Academy of Pediatrics by the same panel; 42 physicians attended this meeting.

The desire to increase physician awareness and acceptance of the programs and services offered was, and remains, a major objective of this project. Prior to the establishment of this project the number of new referring physicians per month was five, with the average monthly referral of new patients totaling eighteen. Since implementation of the project, the average number of new referring physicians has increased to nine per month, and the number of new patient referrals is now 32 per month. The project is, indeed, reaching new physician referral sources and extending its services to an increasing number of new patients.

Patient education activities, always a major thrust of the Arthritis Foundation, have received an increased boost as a result of ARMP funding. The funding has also enabled the Foundation to hire and train two part-time District Coordinators. These coordinators have been active in organizing Arthritis Voluntary Action Committees throughout the State. ARMP funding also provided for an incoming WATS line which was installed October 3, 1974, for individuals who had questions concerning arthritis and its treatment. During the first year of operation, 1,158 calls for information and referral services were received.

In another effort to provide patient education, the Arthritis Foundation contracted with a private organization to develop an all-media patient education program. This program encompassed: development and distribution of statewide news releases including such topics as juvenile rheumatoid arthritis activities, home care physical therapy clinics, and information on "Women In Arthritis"; publicizing the new inward WATS telephone service; preparing slides for audiovisual presentation of services available to arthritics in Arkansas; preparing and distributing 25,000 pamphlets on services available; distribution of a newsletter for arthritic patients, which was expanded from a distribution of 8,000 to 13,000; development and release of television and radio spot announcements, as well as ordering arthritis information exhibits for distribution during the second year of the activity.

During the past year 2,255 literature requests have been filled, in addition to materials distributed through the Arthritis Voluntary Action

Committees which plan meetings and displays in their areas. The Arkansas Educational Television, KETS-TV, presented a special program entitled, "Arthritis: The Confusing Crippler." At the present time, development of five-minute technical tapes on arthritis is being researched by members of the Arkansas Arthritis Chapter's Medical Advisory Committee in cooperation with the educational materials contractor.

The Allied Health Outreach program for victims of arthritis is receiving increased emphasis. An additional physical therapist has been hired with ARMP funds, and Home Care Physical Therapy Clinics have been established in Conway, Clarksville, De Queen, Fort Smith, Magnolia, and Warren, Arkansas. A two-day workshop for physical therapists was conducted with 42 physical therapists and allied health professionals in attendance who received training in special techniques useful in the treatment of rheumatoid arthritis.

The funding of this project has also permitted increased attention to the development of stronger relationships between other groups and organizations that have an interest in the treatment of arthritis. These organizations include: the Retired Senior Volunteer Program, the Arkansas Voluntary Action Program, the Arkansas Association of Retired Persons, the Nursing Department of the State Health Department, the local and county health department units and the county medical societies, with a major focus on strengthening the Foundation's relationship with the University of Arkansas for Medical Sciences.

In addition to maintaining the activities of this program, efforts to serve the arthritic population must be markedly increased. Areas for additional emphasis include:

- A. Increased emphasis in the area of pediatric rheumatology. The problems of arthritis in children are not adequately recognized or treated by the medical community at this time.
- B. Expansion of consultation clinics for primary care physicians, which have been a highly successful, major aspect of the current program.
- C. Implementation of physician education activities in drug therapy for arthritics.
- D. Development of an increased outreach program for allied health personnel involving occupational therapy, physical therapy, and social work aspects in addressing the problems of arthritis. Focus should be placed not only on increasing the personnel available for service, but also on increasing the general level of professional understanding.

The Arkansas Regional Medical Program has fortunately been able to be of some assistance to the citizens of Arkansas in the development of an arthritis program that has reached out into all areas of the State. While an excellent beginning has been possible under the guidance of the Arkansas Chapter of the Arthritis Foundation and its capable Executive Director, the strength and effectiveness of the program are now severely



threatened by the loss of funding support which has been available through the Regional Medical Programs. As the Regional Medical Programs face dissolution under PL 93-641 at the end of June 1976, so does the support for this program. Many proponents of the new law insist that it is simply a phasing out of one program into another. However, in many areas--particularly in Arkansas--the new law means the dissolving of this agency and its programs, with no provision for phasing most of them into any of the aspects of the new agencies being developed.

It should be obvious that we are pleased with the progress of the Arthritis Control for Arkansas project, both in its completed phase and in the current phase which we are continuing to fund. It is our hope that this program can be continued even though under PL 93-641 the Regional Medical Programs will cease to exist at the end of June 1976.

DONALDSON: Thank you, Mr. Warner.

[Recording interrupted.]

DONALDSON:... workshop on centers, and this report has been made available to the Commission. Second, the Commission itself is developing a committee to address itself specifically to centers and center functions. And, I can tell you from the preliminary discussions that the centers are going to be of different types and not one uniform, as I don't know of anybody who thinks they have found the answer to the perfect center.

VOICE: Except a few center directors.

DONALDSON: I'm speaking for the Commissioners. And, on the question of confidentiality--this has been a major concern also of a work group--and the data. Dr. Felts has served on that; he may want to address himself a little bit more to it, but we are concerned with it, and we do not have the official report back from that work group yet, so I can't give you any further specific information. I think with those statements, I'd ask if any of the Commissioners have questions. Yes?

SHIELDS: I would like to ask a question of Dr. Sanders related to, again, the physical therapy program. I, myself, have a gut reaction that the aggressive physical therapy program aids in the crippling of patients with arthritis, but I don't find a lot of evidence to help support that, and I was wondering, what do you have in regard to information, data collecting, or studies that would support that kind of endeavor?

SANDERS: Well, we, of course, do keep evaluations, running evaluations of all our patients, and certainly the problem in evaluating patients with arthritis of course, besides the chronicity and the variability of the disease, is knowing with any certainty the conscientiousness with which the patient carries out their program. So, this enters into the difficulty in evaluating the patient. But, I think that the figures that we have gathered in the first five years of the program seem to bear out that those patients who are conscientious in carrying out their program do not show deterioration of their joints as far as tendons shortening, capsular scarring, and things like that are concerned. Of course, we all



know that none of the currently available forms of therapy are terribly effective in halting the bony destruction, so that certainly some crippling is going to occur in any patient no matter how good physical therapy they get. But, I think that our data suggest that the therapy is making an impact in reducing the number of cripplings that occur because of the tendon shortening, capsular scarring sort of things that we feel are preventable.

VOICE: Is that information--is it possible to make that available to us?

SANDERS: I don't see why we couldn't.

VOICE: One other question along the same lines, when you said that your specially trained physical therapist, going into a school--is he training a faculty member?

SANDERS: Excuse me, he does not go into the school. The student joins him on his rounds, seeing the patient for a brief period of time.

VOICE: That's a student of the school rather than a faculty member?

SANDERS: Right.

VOICE: OK. Thank you.

MELICH: I'd like to ask Dr. Sanders about the arthritis team per se. You seem to be emphasizing the physical therapy part. Do you have other members that would be a part of the team that goes around through the State?

SANDERS: No, we'd love to. We'd love to have a social worker, for instance, but we simply don't have the funds to support such a person at the present time.

MELICH: Why do you feel you would need a social worker?

SANDERS: Well, I think that all patients with arthritis have social problems to some degree, and in some cases these are often overwhelming. Many physicians, in fact I think I'm safe in saying most physicians, are woefully ignorant of the facilities that are available to help solve social problems of families. A social worker knows of all these resources and can often tap them and help solve problems that are unsolved simply because of ignorance of the people involved.

MELICH: I was particularly interested in this because I am the patient advocate on the Commission.

SANDERS: As an ideal, I think a trained social worker would be a very valuable adjunct to an arthritis team.

MELICH: Have attempts been made to invite the current source of social workers into your program as a part of your team?

SANDERS: We have had some fledgling cooperation with the social work people both at the Medical Center and at the School of Social Work, but not any close liaison at the present time.

DONALDSON: Dr. Felts, do you have a question here?

FELTS: Yes; Dr. Jackson, in your prepared statement I believe you made a remark to the effect that there are problems relating to privacy and confidentiality that a large segment of the population may not yet have identified. There have not been many witnesses who have addressed the question of the data bank proposal to appear before the Commission, and I wonder if you would amplify a little bit about your concern in that area?

JACKSON: Well, my concern is unauthorized use by authorized users. That may sound confusing, but once a data bank which can communicate and has stored personal information in it appears, it is no different than a whole national file cabinet of patient medical records, with the single exception that it can be manipulated with speed of light and can be accessed with great ease. There is within that an immense power for good and an immense concern for misuse. And that's all I'm saying. There are now, at the present time, and it probably would surprise you, but if you include national driver registers, if you include IRS forms, if you include the fact that I have been in the military at some time or another, I've done all these other things--there are probably more records on me as a citizen than there are on others, but there is already an average of more than five personally identifiable records within Federal program computers on every citizen in the United States right now. I want our profession, I want our Medical Center to contain medical information and be able to mine that informational mountain of gold. But I am very concerned about the increasing use of person-identifiable, very individual, information on all of us as citizens. And that's all I'm saying. I'm saying, be very careful.

We all wear multiple hats, and I'm on that group in Gaithersburg with the National Bureau of Standards who is trying to come up with some guidelines which will keep us safe from potential injury, data misused by authorized users.

VOICE: Dr. Jackson.

JACKSON: Yes sir.

VOICE: I think our concern is that much of the new information related to research in arthritis will come from the study of arthritics. Therefore, the Commission needs guidance on how this might be safely done. Will this information you are developing at the Bureau of Standards be available to the Commission, will it be helpful to epidemiological studies?

JACKSON: Typical of most of the things we do together under our "fed" hats, it will be a huge volume, probably some 500 pages, which should be available soon. The answer to your question, though, is that the accumulation of data presents you an opportunity to do epidemiological

study. There have been immense and beautiful and wonderful advances that these people have done in immunology and other places. I am personally excited about the ability to look at patterns of disease with these powerful machines and, perhaps, identify things invisible to us always before. I would say, simply, if you can keep it within the professional patient-care setting, without person identity--that's really my hangup: it's really individually identifiable person information. It would be easy to strip that, person identity if it's a heading on a page, decapitate that page, remove that heading. But there are all sorts of manipulations that can still allow you access to clinical information, provide the opportunity under the law for interinstitutional cooperation, and all of these things. They are systems' problems and are not all that hard, and, in fact, they would produce economies because the expense in a data system comes from the number of entries, and if you are manipulating at a higher level with bigger machines a smaller number of components of information, the expense is less. I wouldn't want to give up your dream, but I do want to express concern that we are accumulating another data bank, and there are already five per citizen--five, plus--out there.

VOICE: I have a question for Mr. Warner. Although I am not personally involved in the administration of the remainder of the RMP program in Washington, I do work for the Public Health Service, by which this program is formally being administered. I was concerned about your remarks, which I hope do not get lost in passing, that as the Regional Medical Programs lapse in six or seven months there may be no operational agency organization that would be able to continue this program--which literally has operated a year and a half and is improving itself and certainly must be getting the attention of physicians, patients, and allied health personnel alike--and now you suddenly see nothing ahead. Could you elaborate a little more on how the some of the newer programs, which are, in principle at least, as far as the health planners in Washington are concerned, supposed to pick up and expand the Regional Program? Do you see in practice that this may not come about?

WARNER: Yes sir. The Regional Medical Programs conducted a survey of the 53 programs across the United States to see which would be continued or would be phased into the new law, and only some seven would be phased in one way or another. The others intend to dissolve or continue as a private nonprofit corporation of some kind. The law has often been stated as an amalgamation of currently existing agencies when, in fact, with very, very few exceptions across the country those agencies now in existence must start over again with a different corporate structure and a new board, and, as a result most of the activities will fall out of sequence and out of place. The naming of the HSA's, the agencies; that is, the areas that they are to cover have already been named. The agencies themselves, the applications at the moment are due in on January 19th. That's been consistently delayed month by month, and we now think January 19th will not hold either, it will be another month. They must then go through at least one year of planning in order to receive Federal funds for development once they are in place and approved. It's now estimated that it will be May, certainly no sooner than April, and our guess is now May or perhaps June or even July, before many of them are in place, let alone all of them in place. So it will be a year from then before the funding for developmental activities--which have been the



Regional Medical Programs' activities and that's how we got into the arthritis business, through the development of new programs--it will be at least a year before development funds under the law can be made available. Therefore, it is estimated, it is assumed and seems only reasonable that come July 1, 1976, there will be no more funds for development. It isn't possible under the new law, and under the new law the old agencies have to pass by the boards at that time.

At the present time, the Regional Medical Programs are compiling lists of those programs that they are now funding, such as the arthritis programs throughout the country, that are in danger of a year of no funding, because in essence this means that what has been going on will either come to a complete stop or be very much slowed down for one year before any hope of new funding can come about. Even under some of the new laws that are possible for categorical funding, it will be at least another year or year and a half before they are ready.

VOICE: Well, for what encouragement it may offer you, we have heard several other regions where the Regional Medical Programs are facing the same cut off of funds as of the middle of next year, and I certainly hope some means will be found somewhere.

WARNER: These programs are excellent programs; it would be a shame for them to dissolve.

DONALDSON: Thank you gentlemen very much. Would Mr. Robert Dunkley and Dr. Hanissian come forward, please?

TESTIMONY OF  
ROBERT DUNKLEY  
PARENT OF JRA PATIENT

DUNKLEY: Good morning. I am Robert Dunkley. My family and I live here in Little Rock at 108 Winnwood. Our five-year-old daughter, Mary, has had JRA for three and a half years. I would like to take my time to point out to you some of our family's individual problems and needs, so that you may better assess the total situation in the Little Rock area.

Since we found out that our daughter had JRA our greatest problem was finding good medical care for Mary. She contracted JRA while we were in the military here in Arkansas. After much wasted time at military hospitals we were sent to LeBonheur Children's Hospital at Memphis. There Mary was diagnosed and treated by a pediatric rheumatologist, Dr. Aram Hanissian, and her condition improved. After discharge from the military, we returned to New Orleans, our home. We soon found that there were no specialists in the area to treat JRA. We found that many pediatricians and "adult" rheumatologists were reluctant to treat children with JRA.

We finally moved to Little Rock to be closer to the good treatment facilities at Memphis and Dr. Hanissian, who is treating Mary again.

We feel that there is a serious problem of persons affected by JRA not knowing where to go for proper treatment. We have found that the

different specialists often required for treatment are often isolated by distance and are unaware of each others' services. A treatment facility which provided a comprehensive range of medical services for treatment of JRA would enable patients as well as other doctors to find qualified services quickly and easily. Transportation is a problem for us and others we know. We feel that this should be a part of the services provided by a treatment facility so that it can be utilized to the greatest extent possible.

Another problem we feel you can help in is the financial aspect of providing treatment for JRA. In our case, the Government has been responsible for a large part of Mary's treatment. In the Air Force, she was treated free at the base hospitals. I am now a civilian Government employee. The Government pays over half of my medical insurance premium. We are able to deduct travel and other expenses from our Federal income tax. So, indirectly, much of Mary's treatment has come from the taxpayer.

We believe that if medical treatment were made available through Government-assisted centers, the Government funds normally spent for insurance, military hospitals, and income tax returns could be more economically used, and more persons would benefit from it.

In addition to our own individual needs, we feel that this area has a great collective need for a treatment facility for JRA. We urge you to hasten its establishment so that it can serve our needs and those of our friends.

Thank you.

DONALDSON: Thank you, Mr. Dunkley. Dr. Hanissian.

TESTIMONY OF  
ARAM HANISSIAN, M.D.  
PEDIATRIC RHEUMATOLOGIST  
UNIVERSITY OF TENNESSEE  
CENTER FOR THE HEALTH SCIENCES

HANISSIAN: As a pediatric rheumatologist from Memphis (University of Tennessee Center for the Health Sciences), I would like to express my concern for the lack of support in the area of pediatric rheumatology. Since statistics on arthritis in children are nonexistent, and most of the information in this regard is based on estimates, I would like to present to you some crude data based on estimates to highlight the scope of the problem of caring for such children.

According to some estimates, 250,000 children in the United States suffer from juvenile rheumatoid arthritis. Since there are only few pediatric rheumatologists in the country (6 or 7 in number), most of these children are either left undiagnosed or are treated by nonspecialists.

It is most important to develop comprehensive diagnostic, care, teaching, and research regional children's arthritis centers in selected areas of the country. The center will have the following functions:

- (1) Serve as a regional referral center for providing expert opinion in the diagnosis and management of children suspected of having arthritis.
- (2) Serve as a source for public education so that the public may know that arthritis can affect a young child and induce severe crippling. The public view of arthritis is that it is an old-age disease. That arthritis can affect the child is almost unheard of by the overwhelming majority, so much so that when a parent is told their child has rheumatoid arthritis they become appalled by the news and almost invariably ask if children can have arthritis.
- (3) Serve as a source of education to the medical public, through lectures, conferences, symposia, etc. Most physicians are aware of the problems of juvenile arthritis, but have little know-how in its proper management. Medical therapy of juvenile rheumatoid arthritis is limited to aspirin; when the disease fails to respond to aspirin most physicians choose steroids, usually in much higher doses than are required, with all the anticipated side effects. Because the use of most antirheumatic drugs, such as gold, is rather limited in children for their toxicities, these children are frequently deprived of these valuable drugs. The director of the center will make every effort to coordinate the medical care of the child by educating and encouraging the referring physician in the proper use of these agents.
- (4) Serve as a comprehensive care center in a multidisciplinary fashion. The proper care of a chronic illness such as arthritis requires the help of multiple people, each talented in his or her specific field. A team consisting of a pediatric rheumatologist, orthopedic surgeon, physiatrist or physical therapist, psychiatrist or psychologist, social worker, nurse, occupational therapist, and teacher during a clinic session will evaluate the arthritic child and make a disposition as to the optimal care and rehabilitation, both physical and psychological, so that child and family can be rehabilitated, thus preventing unnecessary agony and physical and mental deterioration.
- (5) Serve as a teaching center. The proposed children's arthritis centers should be within medical schools and will be important sources of teaching medical students, interns, residents, and postdoctoral fellows in the proper diagnosis and care of arthritis in childhood. These young physicians will serve as future practitioners to fill the gap of giving the necessary care to nearly 90 percent of the arthritic population, currently not receiving optimal care.
- (6) Research. An academic center by necessity should perform clinical and basic research to remain in the forefront of medicine. Since the children's arthritis center will be a part of the academic system of the university, it will utilize intra- and extra-departmental and college resources to achieve capabilities of



performing significant basic and clinical research in the field of children's arthritis.

In conclusion, I have outlined a three-pronged approach of patient care, teaching, and research in the field of arthritis and allied musculoskeletal diseases in children. I have also outlined the vast need of establishing regional children's arthritis centers.

The Memphis Medical Center has a drawing area in six states (west Tennessee, north Mississippi, east Arkansas, southern Missouri, Kentucky, and Alabama) with a total population of around two and one half million. If rheumatoid arthritis affects 1 percent of the population, 25,000 persons will have arthritis in this area.

According to conservative estimates, 5 percent of the arthritics are juveniles, hence 1,250 children will have rheumatoid arthritis alone. In my clinic I treat approximately 120 children with chronic arthritis, or around 10 percent of the total number. Since I am the only pediatric rheumatologist in the area, 90 percent of the children are either not seen by a physician or, at best, are treated by general practitioners, pediatricians, internists, adult rheumatologists, or orthopedic surgeons. Since Memphis Medical Center serves as the referral center for the area, it would be natural for a regional children's arthritis center to be located in Memphis. It will serve all of above functions well and act as an exemplary care, teaching, and research center for the region.

Thank you very much.

DONALDSON: Thank you. Are there questions from the Commissioners? Thank you gentlemen very much for appearing this morning.

HANISSIAN: Thank you. Before we depart, I'd like to recognize some of the parents that came all the way from Memphis with us. To my back I have Mrs. Fincher, Mrs. Williamson, (inaudible), and you have already met Mrs. Dunkley, sitting there, and Hilda Brown. Thank you very much.

VOICE: My child was diagnosed with rheumatoid arthritis in May and as a result of the care she has received in Memphis, although she has an extremely bad case she is doing very well, but it is this kind of care that we feel is so important not just for a very few children but for all the children in the region, and that's why we want the center enlarged so much in Memphis.

VOICE: Can I just say one thing, that we've heard similar groups expressing the need--some of them have formed family groups, and I was kind of interested in knowing whether or not the parents such as you've brought here have formed a family group?

VOICE: We hope to form one; this is what we are trying to do. It may be a little while, but we have many interested parties. I also have a child that is 12 and has been under Dr. Hanissian's care for a year and a half. She has lupus, which is in the family of arthritis, and before the year and a half she was under other doctors, and guess work, what have you--we almost lost her a couple of times. Now we are in almost in

complete remission because of Dr. Hanissian. It has been a very good program they have entered.

VOICE: I was going to take the initiative; I'm sure I speak for the members of the Commission, although we get a little tired and bent sometimes traveling around the country, I think we get a great deal of encouragement from learning of the interest and active participation of the parents such as yourself coming to these hearings. It's helpful to us in a real way. Thank you.

DONALDSON: I think I might further state an impression that has emerged that parents of children afflicted with juvenile forms of arthritis often initially discover the presence of the disease, unfortunately in their own family, by crisis. They have often indicated that they feel they are kind of out there alone; they are not aware that anyone else has been confronted with this type of problem, and, indeed, good help is not always easy to find. I would like to quickly inquire from the group that has come in around this, this morning, their impression of whether or not families talking with families has provided any usefulness in the management of these conditions and in developing a realistic attitude and approach to support of children.

VOICE: Because we come from five states, it is a little difficult to all get together, but at each of our meetings there has been at least one parent who found tremendous relief from knowing that there were others who had had the exact same problems that they were now facing, that they had no idea how to handle. When they find out somebody else has that problem and have a chance to talk about it, the problem eases right then, at the very beginning of the problem.

VOICE: Some of the time, if people would just become aware of children that have arthritis, that children can have arthritis. It comes as a great shock when the doctor says your child has arthritis.

DONALDSON: Mr. Shields.

SHIELDS: Just one comment, to remind you that the Commission has a responsibility to prepare the plan and to give the plan to Congress, but then the Congress has to supply the money, and I would hope that you would remember how powerful you really are in terms of helping the actual money be made available and, as I hear all these statistics--I keep hearing there are twenty million Americans with arthritis, that means there's just that many more husbands, or wives, or mothers, or fathers, or friends--maybe that's fifty, sixty, seventy million people who are really concerned. If they would come together with a singular focus and let all their Congressmen and Senators really know how much they care, then I think all of this is of some value because it actually gets appropriated in money available. Now, that's not the case; so I would think that you have a great role to play, and your time will come right after the plan has been given in and don't forget that item.

DONALDSON: Thank you, thank you again. Would Mr. Hunter, Dr. Fletcher, and Dr. Schindel come forward please. Mr. Hunter.

TESTIMONY OF  
DWIGHT L. HUNTER, JR.  
PRESIDENT  
NORTH TEXAS CHAPTER  
ARTHRITIS FOUNDATION

HUNTER: I am sure that in the hearings you have already held, you have heard the sum and substance of what I have to say, because the cavernous unmet needs of the majority of the Nation's arthritics are undoubtedly the same wherever you hear them.

For the record, I am neither an arthritic nor a physician. I am a lay person who got caught up in a cause that now I cannot and will not let go. I am President of the North Texas Chapter of the Arthritis Foundation.

In that context, let me speak for the 190,000 victims who live in the 25 north Texas counties that make up our chapter. In some ways we are luckier than the vast majority of areas because we are so close to the Rheumatic Disease Unit at the University of Texas Medical School in Dallas. The researchers there are available to consult with primary physicians throughout our area. Also, in our largest county, Dallas, we have nine trained rheumatologists in private practice. We have one trained rheumatologist in private practice 90 miles from Dallas.

But I perish to think that this is the best 190,000 people can hope for.

All these figures boiled down to brass tacks mean that 69,255 of the arthritics in our area live an average of 120 miles from a trained rheumatologist.

To serve these people, we would urge that a top priority of any comprehensive attack on arthritis be directed toward:

- (1) Increased training in rheumatology for those physicians already in practice in the smaller communities throughout the nation. The physicians active in our chapter assure me that the majority of cases can be treated successfully by primary care physicians...if that primary care physician is given post-graduate training.
- (2) We would applaud any program that recruited and trained rheumatologists who would agree to go into smaller communities to practice after their graduation.
- (3) We think that any arthritis clinic established in a large metropolitan area should seek some way to develop satellite "clinics" operating at least part time in communities that are 100 miles or more from the parent clinic.

Our chapter's own priority has been research--since 1958, the Foundation has put almost one million dollars from voluntary contributions into the program at Southwestern Medical School--so, as you might expect, very high on our list of priorities would be more money for research--both



basic research to find the cause and ultimate cure, and clinical research that would translate the knowledge we have now into more effective treatment and diagnostic methods to help those people who suffer now and for whom a "cure" in the future will come too late.

DONALDSON: Thank you, Mr. Hunter. Now if we could hear from Dr. Fletcher, please.

TESTIMONY OF  
DAVID KING FLETCHER, M.D.  
RHEUMATOLOGIST

FLETCHER: Background: I am a 40-year-old physician, specialist in the treatment of arthritis and other musculoskeletal disorders, living in an east Texas town of 60,000 population which has a medical service area of one million extending into Arkansas and Louisiana.

Problem: After eight years of private practice in which I have examined and talked with over 6000 patients with arthritic problems, it has become glaringly apparent that the main obstacle to proper treatment for persons with these problems is not the lack of appropriate drugs that might help a particular case; not a lack of workers in medical centers doing research concerning these disorders, but is, in fact, a lack of a physician in or near the patient's own community trained sufficiently in clinical rheumatology to have enough confidence in himself to employ the medicines and techniques necessary for proper treatment.

Causes of Problem:

- (1) Rheumatology is a young specialty and not all medical schools even have a department. Many doctors are in practice who have had no exposure to these problems.
- (2) Those medical schools which do have a department are research oriented (of necessity, because that is the only way that they have been able to get funds to operate). Very few of the departments, even if more clinically oriented, have any personnel who have ever been in the private practice of rheumatology. In general, the private practice of rheumatology is a broad field encompassing more neurology, orthopedics, rehabilitative medicine, and pain control than academic rheumatology. About 70 percent of the types of problems seen in private practice are not seen in the medical school environment.
- (3) This means that the typical medical student will be exposed to some rheumatology but in such a manner that it will not help him much in managing a wide variety of patients in private practice.
- (4) It means that the average internal medicine resident will learn about the five or seven main diseases comprising classical rheumatology (RA, SLE, PSS, AS, OA, gout). Unfortunately, these make up only about 30 percent of the patients looking for help. In this group he will lack confidence in using drugs such as gold, Cytosan, Immuran, and Penicillamine. He will know nothing about injection therapy and will

have very little idea about appropriate physical medicine and when and what type of surgical procedure should be performed.

- (5) It means that your future rheumatologists in training are lab oriented. They are willing to let the orthopedist handle all the musculoskeletal problems, the neurosurgeons all the neck and arm problems, and the anesthesiologists all the pain problems. As a result, the rheumatologist in training has such a narrow scope of his speciality that he believes that he would be bored to death practicing it, so he stays in research or goes out to practice internal medicine.

Recommendations: That rheumatology programs in medical schools should be encouraged to establish clinical fellowships that will train physicians with the desire and capability of going out into the smaller communities and directing the primary care that these patients need. To do this, special, broad-based programs will have to be formulated by academic and practicing rheumatologists working together, and specific funds designated for this purpose would have to be allocated.

#### Summary

- (1) The problem of arthritis is not just the lack of drugs or research--because money has been available for research and not for clinical training, young physicians are trained to be research oriented, and they are trained in "classical" rheumatology.
- (2) Because of the lack of practical, clinical training, the young physician lacks confidence in his ability to treat the arthritides. He will attempt to treat only 10-20 percent of his arthritic patients--and those only with the more common forms of the disease.

Therefore:

- (1) Under the National Arthritis Act, some money should be utilized to set up specific clinical training with none of the money being spent on research or research-related equipment;
- (2) Practicing physicians must be utilized in the training of clinicians;
- (3) If possible, both students and residents should have part of their training outside the walls of the medical school in a practicing physician's office.

DONALDSON: Thank you, Dr. Fletcher. Dr. Schindel.

TESTIMONY OF  
WILLIAM H. SCHINDEL, M.D.  
RHEUMATOLOGIST

SCHINDEL: Dr. William Schindel, private practice of rheumatology in Dallas; Chairman of the Medical and Scientific Committee of the North Texas Chapter.

If we're ever going to lick rheumatoid disease, of course, we have to continue research, continue study until we arrive at an etiology. I don't think that needs to be discussed any further.

If, dealing particularly with rheumatoid arthritis, we talk about severe or moderately severe rheumatoid, we come across the good and bad fact of neuro-orthopedic procedures which have helped relieve pain and have helped to provide some more functions for folks who are pretty badly afflicted. As people who could not walk, could not get out of a wheelchair are now more or less pain free and over a period of months after surgery do begin to function, we find that their total care is more and more complicated, and it requires more of a team approach. I think that these things can be done only in some sort of regional center on referral from a trained clinical rheumatologist also in the area, where we can get a whole team together to work (how anyone accomplishes these things is beyond me). But, we do need orthopedists, we need physiatrists, we need physical therapists, vocational rehabilitation, and all these people have to get together over the body to discuss these things with the patient, with the family--to evaluate, reevaluate, and treat. This comes again to the other point, we need more trained clinicians who will be out in outlying areas who have had, perhaps, some exposure to the classic training in rheumatology clinics, but also have had the experience of working with private rheumatologists--seeing the headaches, the problems we put up with in the office--before they go out to call themselves private rheumatologists. Thank you.

DONALDSON: Thank you very much. The emphasis obviously from the two of you is on the development of a new type of fellowship which would be clinically oriented.

SCHINDEL: We never met each other until today--right now.

DONALDSON: And this, again, is a suggestion that has occurred in other testimony. You would see, then, that the fellowships as they currently exist are too research, too laboratory oriented, too sterile in the everyday problems, I would gather?

VOICE: Yes sir, I think that the basic problem is that most of the people who are teaching your rheumatologists have not had much practical experience themselves in the private practice. Most of them, I would venture to say, have never scrubbed on a total hip. Most of them have never put in plastic joints. When they recommend that a patient should have surgery, they are really talking about sort of a dark field that they don't really don't know any practical thing about. When they follow a patient postoperatively, they really don't know what was done inside there, and it's difficult for them to manage that patient and know when to



push him and when they can't. I think I was lucky in my particular training program at the University of Alabama because I was told from the very first that even though I would be acquainted with research techniques and expected to do some research, mostly clinical, that I was being trained to go out and start a new unit out in the boondocks, and that's what I intended to do. In my small town, we have a very active surgical program, a very active physical medicine program, and I think that we have become in eight years a local center. When I run into problems, then I feel free to send them to Dr. (inaudible) group in Dallas, but that would amount to five or six patients a year, we handle the rest of them there. But the basic problem is that we have people who--I interviewed one last week who'd had a year of immunology and rheumatology and an internal medicine residency. He says he simply does not have enough confidence in himself to come out and practice rheumatology. He just can't do it. He's going to practice internal medicine, and he'll practice a little rheumatology. Well, I think when that happens you have wasted one of the few fellowships that are available in the country, you've just thrown it down the drain.

DCNALDSON: Yes.

VOICE: I'd like to ask you, when you were in medical school, were you motivated by a fellowship to go into rheumatology or what really inspired you in spite of the fact that there were so few of the rheumatology students around?

VOICE: Right. Money.

VOICE: I know, but did you get it through a fellowship?

VOICE: Yes, through a fellowship.

VOICE: That's what I wanted to know.

VOICE: That was precisely the reason that I took it. At the time, I was broke. They were offering a fellowship in rheumatology and neurology, and I became a rheumatologist by accident--and have not regretted it.

VOICE: This is something we're trying to emphasize in the Education Committee--that without fellowships you don't get rheumatologists and without rheumatologists to train other students there is just no way to go. Thank you.

VOICE: I'm Dr. (inaudible), a local physician here in Little Rock. I'd like to know on what scale--the picture they are presenting here is one of scarcity, we have a tremendous scarcity of rheumatologist in the United States.

Anytime that there is a scarce item, that intrigues people to get into it because it must be lucrative. Now this is something I'd like to know. Is the rheumatologist on the low scale of the medical profession? This is a point that we have to bring out. People are avoiding their doctors, as I sit here. In medical school apparently, the medical students are told to stay out of rheumatology because you are not going to make a lucrative

life. I mean, you want to live a certain life style, and, as you heard recently, the surgeons are very upset because they have their overproduction of surgeons, and I believe the Board of Surgery is beginning to start to limit, they are starting to say they are going to make quotas. Now here you have a group that needs people and yet you can't get them, and I'd like to know why. You said that there is a certain amount, it had something to do with the pay scale of doctors.

VOICE: Well, Doctor, people with chronic diseases are poor in the first place. No, we're way down on the pay scale.

VOICE: Right, so this is what this Commission--they have got to equalize that; they will have to make up the difference.

VOICE: As far as I am concerned, I'm equal enough. I'm making a living.

VOICE: Well, I know, I was a Federal employee; I was not in private practice.

VOICE: I don't think the schools ever say, "Do not go into rheumatology, you won't make any money." When I went to medical school 20 years ago they didn't mention it. We had two hours of lecture on rheumatology, and that was it.

DONALDSON: I think that's the key that we have seen as we have gone around the country, that the exposure of the student to rheumatology is so limited. Many schools don't even have a rheumatologist, let alone a section of rheumatology. Thus the opportunity for the student to be interested in it is way, way down, and that is one of the things that the Commission is going to address itself to. If there are no other questions, then I thank you for appearing, and we would ask May Jackson, Dennis Morris, and I believe Ted Newman is going to speak for David Ray. Please go ahead.

TESTIMONY OF  
MAY JACKSON, M.S.E., O.T.R.  
PRESIDENT  
ARKANSAS OCCUPATIONAL THERAPY ASSOCIATION

JACKSON: I'm May Jackson, and I'm Assistant Professor of Occupational Therapy at the University of Central Arkansas in Conway and President of the Arkansas Occupational Therapy Association. I appreciate the opportunity to speak to you, panel of Commissioners, on behalf of our state occupational therapy association.

The Arkansas Occupational Therapy Association would like to join with other health care professions in expressing its concern for the well-being of the arthritic patient in Arkansas. The progression of disease and disability in rheumatoid arthritic patients has long been a focus of treatment by occupational therapists nationwide. According to statistics from the Arkansas Chapter of the Arthritis Foundation, Arkansas itself has almost 200,000 persons afflicted with arthritis and other rheumatic



diseases; almost 3,000 Arkansans are newly afflicted each year; approximately 23,000 persons living in Arkansas are disabled from arthritis either totally or part of the time. Society's concern in such a major cause of disability is mandated because of its staggering economic consequences; on a more human level, society must also recognize as equally important the tremendous emotional burden of arthritis to both arthritics and their families. Occupational therapists, operating from a basis that all humans--regardless of disability--have a right to as full and productive a life as possible, can help to reduce both the economic and personal cost of arthritis.

The evaluation and treatment of an arthritic client by an occupational therapist focuses upon the person as a "whole" individual. Evaluation procedures with which the occupational therapist has expertise include joint range of motion and muscle strength testing, activities of daily living evaluation, homemaking evaluation including architectural barriers in the home environment, evaluation of the need for splints and/or adaptive equipment, pre-vocational evaluation where job performance capabilities are in question, and structured psychological inventories to assess the level of the arthritic's psychological adaptation. Treatment procedures utilized by occupational therapists in working with arthritic clients include the following: range of motion and strengthening exercises; splinting; instructing the client in methods to enable self-care independence if possible, incorporating adaptive devices where necessary; instructing the client in techniques for joint preservation to help avoid unnecessary trauma to weak joints; instructing the client in simplified and labor-saving methods for homemaking, again incorporating adaptive devices or specialized equipment where necessary; and provision of a therapeutic atmosphere which gives the client a supportive and constructive outlet for his fears and aggressions while at the same time challenging him to achieve the maximal level of independence possible.

Currently, several agencies and facilities provide specialized medical services to arthritic persons living in Arkansas. For example, the Arkansas Chapter of the Arthritis Foundation conducts a physical therapy home care program statewide and hydro-pool therapy programs in Little Rock and Fayetteville. Leo N. Levi National Arthritis Hospital, the University of Arkansas Medical Center, and the Arkansas Department of Home Health Services all help to meet the needs of the arthritic for specialized treatment. None of these facilities or agencies employs an occupational therapist. At only three institutions in Arkansas--Hot Springs Rehabilitation Center, Central Baptist Hospital in Little Rock, and Baptist Medical Center in Little Rock--are occupational therapists employed who occasionally see arthritic patients among their caseloads. While the physical therapy home care program of the Arthritis Foundation has overlapped somewhat into the traditional occupational therapy areas of splinting and adaptive devices, other needs of arthritic persons remain unmet.

It is recommended that these unmet day-to-day and rehabilitation needs of arthritic persons in Arkansas can best be met by involving occupational therapists in home care programs and in all clinics and institutions which provide specialized services to arthritics. That occupational therapy traditionally plays an important role in the treatment of arthritis is



highlighted by the fact that the author of a major Arthritis Foundation publication, "Self-Help Manual for Arthritis Patients," is an occupational therapist. Federal monies could be used to make this role of occupational therapy a reality in Arkansas--and thus meet the needs of Arkansas' arthritic citizens in a much more comprehensive manner than is currently possible.

DONALDSON: Thank you very much. I can only tell you that when my oldest daughter knew that I became involved in this program--she's an OT, and she said, "Daddy don't forget the OT's Mr. Morris."

TESTIMONY OF  
DENNIS MORRIS, R.P.T.  
CHIEF PHYSICAL THERAPIST  
ARKANSAS CHAPTER, ARTHRITIS FOUNDATION

MORRIS: Arthritis in any of its forms is a tenacious and confusing disease. It is tenacious in that it may be reasonably controlled for 5 or 10 years and then suddenly begin to run rampant throughout the body. It is confusing for the same reason.

Arthritis is a daily continuous disease which ideally demands a daily continuous program aimed at it. Our primary care physicians and even our specialists cannot treat the arthritic patient one time a year, or one time a month, or even one time a week and expect to totally control the disease and totally satisfy their patients and their families. This disease is not so simple as "to take a pill, is to get cured."

I would probably be safe in saying that at this very moment, there are arthritic patients in every hospital and nursing home in Arkansas. I would also be safe in saying that the more the patient knows about arthritis, the better he or she is equipped to cope with it. This also holds true for the physicians and the paramedical personnel who provide much of the supportive care arthritic patients receive. If our professional people are knowledgeable about the disease, they are more apt to be able to instruct the patient and the family in a proper two-pronged program against arthritis: (1) a good medical program, and (2) a daily home program of rest, heat, and proper exercise.

It is my belief that our physicians, physical therapist, O.T.'s, nurses, and social workers should have a better base of knowledge about arthritis before they become a part of our work force.

I believe educational emphasis should be strengthened in the following areas:

- (1) Every medical school needs a staff rheumatologist to help instruct our medical students. There are approximately 38 medical schools in the U.S.
- (2) An organized continuing education program should be mandatory for all primary care physicians. Many of our general practitioners

do not feel comfortable treating arthritis, and they readily state to the patient that they either do not know what to do, or that there is nothing that can be done.

- (3) Supportive branches of medicine have flourished in the past 10 or 20 years. And today millions of arthritics are getting advice, treatments, and education about arthritis from nurses, physical therapists, and occupational therapists. All of these groups can tell you that arthritics probably have swelling, pain, soreness, stiffness, decreased joint ROM, and other clinical symptoms. But very few of us can explain to the patient why they are stiff in the mornings, or why they must take their medication daily, or why their fingers swell, or any of the other hundreds of whys. We must improve the education of supportive medical personnel while they are in school, with better educational aids and better information about arthritis which is aimed at their particular specialty.
- (4) So far I've only mentioned that we must put much educational emphasis on providers of medical care; we must also educate our masses. I say masses because there are approximately 20 million people in the U.S. who have arthritis serious enough to seek medical attention.

It still amazes me that I continue to meet people from all walks of life who still think that arthritis is for old people, or is not very painful, or that it can be cured by the bee sting, or rubbing gasoline on joints, or by wearing the copper bracelet.

I can't cure arthritis and neither can anyone here at this Commission. But we do have the means of letting the people know that there is help available. Because where there is help there is always hope.

DCNALDSON: Thank you. Mr. Newman.

TESTIMONY OF  
DAVID B. RAY, JR.  
DIRECTOR  
DEPARTMENT OF SOCIAL AND REHABILITATIVE SERVICES  
ARKANSAS

PRESENTED BY TED NEWMAN

NEWMAN: "I have been asked by Don Riggin, Executive Director of the Arthritis Foundation, Arkansas Chapter, to present testimony concerning the unmet needs of the arthritic and to state possible ways our department can help resolve some of these needs. I have also been asked to make recommendations regarding the National Arthritis Act.

"In the Department of Social and Rehabilitative Services, we have two large divisions who provide considerable service resources to the arthritic. These two divisions are rehabilitation services and social services.

"The rehabilitation division is designed to enable handicapped persons to improve their employability. Services which lead to this goal include training and retraining, guidance and placement, and the payment of support costs such as medical expenses, tools, and tuition fees.

"The rehabilitation division has as a first priority the serving of the severely disabled person. This major priority includes the severely disabled arthritic. With this priority, the rehabilitation division will be able to provide more intensive and comprehensive services to the arthritic than have ever been possible in the history of that agency.

"In keeping with this priority, rehabilitation is reexamining their counseling and training procedures and placing more and more emphasis on the severely disabled. This is a change from the past, and one could speculate that the arthritic will be receiving more services from this division.

"In order for the general population to know about the priority changes in our rehabilitation services division, we are using our own newsletter, forums such as this one, and staff reorientation to emphasize this new priority.

"Beginning October of this year, our social service division began a new and expanded service program for disabled people. This division can, through the use of its Title XX money, either purchase or provide new services to the eligible arthritic. New and expanded services include chore services, day care for adults, employment services, health-related services, home-delivered meals, training and education, transportation services, homemaker services, home management services, and special services for the disabled.

"We anticipate being able to expand our capability greatly over the next several months in assisting the arthritic, as well as other handicapped people, through the use of the new Title XX program.

"Although we have considerable service capacity to serve the arthritic, there are other programs needed. It is my opinion that we need to have Federal grant support to enable specialist groups to develop research and demonstration programs especially designed for the arthritic. Our department is a general human service agency, and many times we are prevented from being able to develop the specialized impact programs for one special group. We need the expertise of these research and demonstration efforts to enable us to gear our general programs towards the arthritic as well as other disabled persons.

"It is my recommendation that funding be made available to enable the specialized arthritis agency to develop and maintain programs which specifically impact on the employability and services to the arthritic."

Now that is Mr. Ray's statement; I'd like to just make a short statement myself. Several years ago I had the privilege of being a consultant to the Arthritis Foundation here in Arkansas, and we worked on a program called MAIL, or Mobility and Independent Living. This program



included physical therapy in the home and also appliances and self-help devices. This is not a simple answer, but it seems to me that simple things like a carpenter to go in and fix grab bars and develop slide boards is something that sometimes we miss--it's needed, but we just don't get around to what are rather simple things like a ramp on the front porch. These sorts of things are really much more important than sometimes we feel they are, and I would emphasize in this Act that there be made flexible money for programs like the Arthritis Foundation who can continue this type of home help aids. As simple as they may be, sometimes they are the everyday things that the severely disabled person needs and needs badly. Thank you.

DONALDSON: Thank you. Are there any questions from the Commissioners? Yes.

VOICE: One comment, then a couple of questions. An RMP Program in Tucson is doing the very thing that you are talking about. They have a carpenter going out and actually studying a home modification program, so it's certainly something that others have been thinking of as well.

NEWMAN: We were successful here, but, as many times occurs, project money runs out.

VOICE: I have a question. Have any of the agencies currently looked into the possibility or feasibility of using some of the manpower money, from the Developmental Manpower Act, under Title II, Title III, for the perpetuation of programs like that?

NEWMAN: I can't answer that.

VOICE: Pass the word around; there's a lot of money out there that could assist in these programs.

NEWMAN: I agree there is a lot of money there.

VOICE: I would like to ask a question of May inasmuch as I have to attempt to represent all of the allied health people, and it's easier for me to represent physical therapists; I need all the help I can get from the other professions. You mentioned the problem of not being an active member of teams, and so forth. I wanted to know if you would elaborate on it a little bit as to why, what the problem is in occupational therapy. Is it related to fees?

JACKSON: I think you have to look sort of historically at the position of allied health in Arkansas in general and the fact that rehabilitation needs by and large are not well met in any area in Arkansas. Additionally, for many years the majority of occupational therapy schools were in the northeast, the north central, and down the west coast regions of the country. People tend to stay to work where they train, where they do student affiliations. We, for example, are now in our third year of existence--dear heavens, I can't even remember, it might be our fourth--at the University of Central Arkansas and have to send the majority of our students out of state on clinical affiliation. So we lose quite a few that way. The lack of knowledge of the role among physicians trained locally

who do not see occupational therapists assuming this role--I think the reasons are really pretty extensive.

VOICE: How would you see that Federal money could really help?

JACKSON: If Federal monies were to make available several positions for occupational therapists that could be filled by competent experienced people, we could immediately, say for example very concretely, enlarge our class size and take more students, who then would be able to train here and would be more likely to stay here, would be able to expose physicians here to rehabilitation in arthritis and sort of do a consciousness raising in that way.

FELTS: Mr. Newman, the social and rehabilitative services departments in most states and areas are confronted with a whole series of problems relating to how to supply services and how to finance them. Do you have any approximation you could give us from experience as to the relative economic needs in some of these broad areas? For example, are most patients with whom you are confronted with arthritis, do they have adequate resources to finance patient care as perhaps contrasted with social or rehabilitative services?

NEWMAN: Of course, the group we have would not, but we wouldn't see normally, other than in rehabilitation, the person of middle or upper income. Most of the people we deal with do not have the resources to purchase the medical care at all, so it's up to other support.

FELTS: Has Medicaid been very helpful in this regard?

NEWMAN: To some degree, but inadequate. I think you could say inadequate, yes.

DONALDSON: Are there any other questions? Yes.

VOICE: I'd like to know if you have in the State of Arkansas a law that requires new buildings to be adapted for the handicapped?

NEWMAN: Yes, we do have an architectural barrier law in Arkansas. I don't know that it affects private facilities. It does affect public facilities and, of course, the buildings built by State government do have to meet this law.

VOICE: I'd like to comment from some personal experience; the law is on the books, but I don't believe it is enforced well, and, additionally, I'm not sure that architects by and large are really cognizant of all the different requirements of the law. One architect was quoted in construction of a building that I know of--I hate to say this statement, but this is a direct quote, "Keep the cripples on the first floor." That was in relation to not putting an elevator in. So it's there, the law is there.

DONALDSON: No other questions, thank all of you. We had asked Judith Carey, Dr. Wilson, and Dr. Clark to come forward. May I remind each of you to please identify yourself, and let's start with Dr. Wilson.

SUBMITTED STATEMENT OF  
T. E. WILSON III, M.D.  
RHEUMATOLOGY AND INTERNAL MEDICINE

The Executive Director of the Mississippi Arthritis Foundation, Mrs. Peggy Wellford, has informed me of the meeting in Little Rock, November 12th. She has asked me to be present and appear, if necessary, before the Commission. I practice internal medicine with a major interest in rheumatic diseases. I have been in practice for 10 years. Approximately 75 percent of my practice is in the field of rheumatic diseases. Most of my practice is a referral type practice, and the majority of the patients are referred because of some complaint of arthritis.

I would like to point out that in the State of Mississippi there is no full-time board-certified rheumatologist. We have one University Medical Center. In addition to medical education, it has programs in a number of allied health professions. There is no department or division on rheumatic diseases in this complex. We have not had a rheumatologist in the Medical Center for 10 years. I have been trying to help in this situation by part-time affiliations with the University Medical School and in the adjacent V. A. hospital. In addition to my office practice, I have staff affiliations with two large community hospitals and see a number of patients in consultation in these centers.

In fairness to the University Medical Center and, specifically, the Department of Medicine, there has been during the past 10 years an effort to obtain an academic rheumatologist. However, I understand that the demand is great around the country, both for chairmanship of rheumatic divisions and for supporting medical staff in rheumatic centers. Apparently, facilities for training academic rheumatologists are limited, and funds have been unavailable for establishing more training positions. I feel the Mississippi situation is further complicated by a lack of funds to establish a program that would be attractive to an academic, full-time, rheumatologist.

In view of the above situations, I feel that the most urgent need for meeting the problem in arthritis is more medical education of physicians for academic full-time rheumatology positions in medical centers. I feel that each university hospital should have a division of arthritis with appropriate staff and laboratory facilities to teach medical students, interns and residents, and paramedical personnel, in the diagnosis and treatment of arthritis problems. I personally do not feel that each medical school needs to be a research center. For young physicians who desire to go into academic rheumatology or research, training could be obtained in the designated research centers if necessary. Other physicians and allied health personnel who have been trained in the university hospital setting would be better prepared to go back to their community to serve in a primary position with a strong background in rheumatic diseases.



We have been most fortunate recently in Mississippi with the opening of the Mississippi Methodist Rehabilitation Center. I believe this center and similar centers could well be utilized in the management of severe arthritis problems, and those that have become primarily a mechanical orthopedic problem. Centers such as this could be a referral center, or could be a primary center with a satellite clinic program. Physicians could then be brought to the university center and the rehabilitation center for a refresher course in diagnostic and current surgical advances.

I further believe that regional or national teams of rheumatologists could be formed as a speaking program, traveling to medical schools or large community hospitals or State and local medical societies, with appropriate audiovisual support, and serve as a small traveling seminar to help physicians keep abreast of the newest trends in rheumatic diseases.

The above is forwarded to you with hopeful consideration that the National Arthritis Act will become a reality for the many patients who are afflicted with arthritis and related musculoskeletal diseases.

TESTIMONY OF  
T.E. WILSON III, M.D.

WILSON: I'm Dr. Wilson, members of the Commission. I'm from Jackson, Mississippi. I practice internal medicine with primary interest in rheumatology.

Most of my training in rheumatology has been on-the-job training out of interest. I'd like to point out that I find myself in rheumatology because of a professor that was in the medical school at the University at the time, Dr. Fred McDuffey. We haven't had a rheumatologist in the University Medical Center. We don't have a section of rheumatic disease. I'm in private practice, although I do direct the outpatient University Clinic a half a day a week.

I've also been associated more recently with the new Mississippi Methodist Rehabilitation Center, which has been open about five months now. I've been a consultant, part time, at the V. A. Hospital, which is also adjacent to the University Medical Center. Just in the past several months, we have had a full-time rheumatologist in the V. A. Hospital, but her period of time there will probably be two years because her husband is taking a residency program in the university in surgery. So we anticipate that she will not be there after June of next year.

I mention this to point out that in our State and our region we do not have anybody that would be considered really under the present classification of full-time rheumatologists. We don't have a rheumatologist at all in the University Medical Center. At the present time, the student enrollment has reached 150 students a year, and this is leaving this group of young physicians without exposure to a strong program in rheumatic diseases. In addition to this, we haven't had a full-time rheumatologist in 10 years, and this leaves a large number of physicians who are practicing without a formal background in rheumatic

diseases. In using the word arthritis here I'm also referring to other problems of the musculoskeletal system.

Much of what I would have or might say in the next few minutes has already been expressed. I think as far as our problem goes it's very similar to the problem in Arkansas as pointed out by Dr. Lipsmeyer, and I'd like to sort of second her presentation. Dr. Fletcher points out that he's been in practice 8 years; I've been in practice 10 years. I've seen I don't know how many patients with rheumatic problems and musculoskeletal problems. Many of these could have been handled by a family physician with some basic background in rheumatic diseases. Many of the problems I see are as simple as a trochanteric bursitis or a herniated disc, down to a scleroderma or polyarteritis. The point being that most physicians in our area are not well informed, or well enough informed on the basic day-in and day-out management of musculoskeletal or rheumatic problems.

At the present time there is little formal education in our area in this particular field. I think it is important to point out that if there was a rheumatologist in the University Medical Center, I'm sure it would have a domino effect in the opposite direction, in that it would tend to attract other young physicians into the field of rheumatic diseases. I feel that exposure is the main factor. We've had gastroenterology with no full-time people present in the past couple of years, and nobody has gone into gastroenterology. We develop a strong field in hematology, and it immediately attracts two, three, or four young residents into the field of hematology. So I think the nucleus of the whole situation is a strong rheumatic section. I don't feel that in our region it should be concentrated primarily in research; it should primarily be a clinical program, certainly with some research and laboratory emphasis. I think at the present time we are making steps towards developing a real center, but again it's going to require more people, which is going to require more funds.

We've recently opened the Mississippi Methodist Rehabilitation Center, which is physically attached to the university. It's a joint venture by the Methodist Conference, the State (as far as the land is concerned), sharing of some services with the university, and support from the Department of Vocational Rehabilitation. In our clinic in the Rehabilitation Center, at the present time we have an internist rheumatologist--myself; we have an orthopedic surgeon; we have someone for physical therapy; occupational therapy, orthotics, bioengineering, radiology, and laboratory services are readily available; there is a counselor for vocational rehab; there is a dietitian; there is someone from the nursing service; there is a representative from the Arthritis Foundation; and we also have access to an audiovisual department. All of these are readily available on the same floor, but we do lack personnel; we lack more experienced physicians.

As far as the patient problems in our area, it's the transportation. There's no close, adjacent, nearby facility for looking after patients with rheumatic diseases other than primary physicians, and, as I pointed out, this is somewhat of a weak link. Cost, obviously, is a problem. Transportation to and from medical facilities, appliances that might be necessary, surgical cost, and laboratory and x-ray are all economic

problems. Some of this is covered by private insurance, others by Medicare, Medicaid, Vocational Rehab, and V. A., but one of the problems is that there is a lack of cooperation many times between various private and public, government-type, hospital services.

My basic feeling at the present time for our center and our region is that we need a full-time academic or full-time university-based rheumatologist with rheumatic support in laboratory, x-ray, occupational therapy, physical therapy, and other allied health parameters. Then we could get into an active satellite program, if that was necessary. However, we're trying to operate, and are operating, two satellite clinic programs through the rehabilitation center, which is funded through the Regional Medical Program which might expire come June, and we'd lose this money. We are also opening up two more clinics, but the staffing is short, and the cost is expensive going out in these outreach programs. With more people and more exposure, I think these needs could be met. Thank you.

DONALDSON Dr. Wilson, I'm going to interrupt some of our procedure to get into a little questioning with you immediately if I might. Did I understand correctly that your University Medical Center has not had a full-time rheumatologist for 10 years?

WILSON: Ten years.

DONALDSON: What seems to be the greatest impediment?

WILSON: Well, my understanding is that there are not a great number of rheumatologists, either academic or research oriented, available around the country, and the demand upon them is great. They are attracted to the centers in areas where much of what they need in the way of help and laboratory and financial support is available. The problem in our region, obviously, is that we don't have the money in the State, or it hasn't been made available through the State legislation or other sources to meet the needs that would attract a full-time rheumatologist.

DONALDSON: How about other specialty divisions within medicine? You mentioned that you had not had someone in gastroenterology, I believe, for a period of time.

WILSON: A good three years now we have not had a full-time gastroenterologist.

DONALDSON: Does there appear to be any problem within the medical school itself in priority determination on specialty divisions?

WILSON: Not that I'm aware of.

DONALDSON: But there is a funding problem?

WILSON: I think in a large part it's a funding problem to attract not just one person but a team of people. That's my understanding.



DONALDSON: Are there other questions from the Commissioners for Dr. Wilson?

VOICE: Yes, I wanted to ask--when we heard from a number of people concerned with the practical side of rheumatology this morning, only one has mentioned pain. I was wondering if you would like to say anything for the record about the management of pain, whether it could be better managed, the tools you have at the moment are adequate?

WILSON: Well, they're not fully adequate. Pain remains a big problem. Until the primary cause of many of these problems is found, that pain is going to remain a problem. But to relieve this pain, at the present time, besides drugs, we are going to have to rely on bracing and splinting and OT and physical therapy and surgery and these kind of allied, ancillary type helps.

VOICE: Thank you.

DONALDSON: Just one last question from me, Dr. Wilson. Again, I'm concerned about the core curriculum of your medical school for your 600 students in the four classes. Without a rheumatologist, what is your assessment of their exposure to rheumatologic problems during their medical school tenure?

WILSON: Well, it's minimal. It's not adequate at all, in my opinion.

We have a fairly strong department in cardiology, like many places. Cardiology is a popular subject. There are many people attracted into cardiology for various reasons, and cardiologists that are trained in the University Medical Center seem to stay in that community. Just like gastroenterologists, two or three that are in clinical practice now in Jackson trained at the university and went out into clinical gastroenterology.

The same has been true in hematology, cancer, chemotherapy. I think the same would be true in Jackson if there was a rheumatologist. I think young physicians are attracted by departments that can create an interest, whether it's in electrocardiography, or whether it's in interpretation of immunologic tests and things.

DONALDSON: Thank you very much. Dr. Clark.

TESTIMONY OF  
GLENN CLARK, M.D.  
FORMER CHIEF OF RHEUMATOLOGY  
UNIVERSITY OF TENNESSEE, COLLEGE OF MEDICINE

CLARK: I am Dr. Glenn Clark. I am currently in the private practice of rheumatology. I would like to go back into history a few years.

I was educated by the Arthritis Foundation, had a fellowship at Johns Hopkins University, one of the first years they offered one, and I came to the University of Tennessee in 1957 to start a training grant there when the NIH first started one of these programs. I directed this program, was professor of rheumatology there for 12 years, and during this time we developed programs in physical medicine and team research. We trained 26 full-time rheumatologists on our training grant and developed a teaching program. We were extremely fortunate in that we were heavily financed by the Federal Government, perhaps because we had some pretty good grant writers and a lot of good research ideas. We did prostitute some of these research grants by getting faculty members who were mostly in research but had a lot of their time spent in clinical teaching.

I spent the next six years as Director of the Medical Center and the last four years I've been in a group of four physicians who are all full time in rheumatology. We have no Federal support. We have in the past four years put 9,000 patients onto our roster, whom we see either on a consulting or continuing basis. We see 1,000 patients a week in the office.

We have ancillary personnel, including 12 ladies of various skills. We operate a 45-bed rheumatology service across the street in a wing of the Baptist Hospital, and one of my partners is also the director of the Methodist Hospital program. The center in which we operate has some 6,000 beds.

I'd like to say another thing before I go on, that is that we have no trouble at all financing our program. We do it through the usual means of support, in contrast to what has been said before, especially from the Arkansas Medipak. I might add that a good portion of our patients come from Arkansas, southern Missouri, Kentucky, western Tennessee, northern Mississippi, and Alabama, because of the location of Memphis as the center of this area. The Arkansas Medipak Program is especially a good one, and I'd like to commend them to the Commission because they do support completely all kinds of services required including extensive hospitalizations for orthopedic surgery, including total hip and knee replacements, which form a big part of our practice. We have no means testing in our clinic.

People come in and say they want to be treated, and then we have them write down who they think might pay it. If we can get it, we get it; and if we can't, we just forget it. We've found another very interesting thing and that is, it costs less to do it that way than to hire a whole bunch of people to try to find out who has money and who hasn't. It's cheaper to just provide the care and forget it if you can't collect for it.

The last thing I'd like to say is that our clinic has a cash flow or collections from all these various agencies of approximately 750,000 dollars a year for four doctors. I'd like to go on with my formal statement, I'm sorry I've taken so much time in telling about the past.

There can be no doubt that the only reason for any program in medicine is the improvement of patient care. I kind of get tired of people talking about priorities. This is the only priority. However, it is axiomatic that good patient care is impossible without progress and understanding of disease and improvement of methods of treatment, and this is research. Increased knowledge is wasted unless we have adequate manpower and communications to apply the latest knowledge to patients. That's education--there is no separation of all these things as far as I can see.

The old concept of a "regional center" was that of a centrally located collection of bricks and mortar engaged in the development of expertise in the laboratory, the so-called team approach to rehabilitation, and the palliation of the ravages of a chronic, incurable disease. I think that most of these centers were related primarily to rehabilitation.

However, rapid strides, especially by orthopedic surgeons, in the past decades have made most of the problems of arthritics solvable in short periods of time in the hospital or as outpatients. (Hand surgery, total hip and knee replacement, the Keller-Hoffman procedures, all of these things have offered very short-term treatment and cure of many of the worst problems.)

Finally, the treatment of the so-called malignant collagen disorders, such as lupus, has made great strides with the support of sophisticated laboratories such as that at the University of California. I am sure that there will be even greater advances in the future, but I believe that our first priority at the present time is to be sure that the good things which have been done for some people be made available to everybody, that ample support be given to the continued effort to find the cause and cure of rheumatoid arthritis.

My recommendations regarding regional centers are:

- (1) That we take advantage of already effective programs, especially in the private sector, and that we kind of develop a community of collaborating people to take care of patients, with the support coming from any source possible, and the remainder of the support, hopefully, coming from Congress.
- (2) Manpower needs, especially at the junior levels in academic medicine, should be supported and subsidized, since this is the source of all future improvements in research, education, and, above all, patient care. I'd like to say at our university we have four full-time professors of rheumatology; we have pots full of fellows; but we just don't have the instructors, assistant professors, and people who bear the brunt of the teaching and patient care. This is where the real need is, for manpower at the intermediate level on the firing line.



- (3) A communication network involving computers and television should be established so that the benefits of centers be available to every physician and patient, in even the smallest community.
- (4) I think that really the biggest problem that we have is the fact that our hospitals have gone broke. We have a big city hospital that is running a deficit of about 11 million dollars a year now, and also is getting some 16 million dollars a year out of the property tax to support this, and yet they still are not able to keep up. I think that one of the biggest reasons for this is that they spend 2 million dollars for the payment of interns, residents, and fellows, and they spend another 2 million dollars on faculty people to supervise these people. I think that Congress should give a very real look at taking some of the burden off of the local taxpayers and off of Medicare and Medicaid to some extent to support these hospitals that are not able to get along on what they get from public funding. That's all I have to say.

DONALDSON: Dr. Clark, to amplify that last point you made, a little, what is the bed occupancy rate in this hospital that you cite?

CLARK: I think it's approximately--it used to run over 100 percent, because they would discharge some patients and put another patient in that same bed the same day. But then we start having periods of strikes and shortage, and big portions of the hospital would be closed down because they didn't have the money to pay nurses, and various other problems. Then they have also been closed down partially for reconstruction, but when I left as Medical Director the occupancy was about 90 percent.

DONALDSON: Is the area generally overpopulated concerning beds? Are there excess beds projected for the population need?

CLARK: We have certainly all we need, in my own opinion. The bed occupancy, of course, varies. During the peak seasons, you can't get a patient into either one of the major hospitals. We have one hospital that has over 2,000 beds, and sometimes we go for months on a waiting list; then, the next summer they may drop down to 60 or 70 percent. The 45 beds that I have charge of have around a 90 percent occupancy.

DONALDSON: One other question from me, Dr. Clark, pertaining to your views relating to manpower. As you are undoubtedly highly aware, there has been a national philosophy away from specialization, as far as Federal subsidization is concerned, and back more towards stimulation of primary care, and, as a result of this, it appears that training programs have been drying up for specialists. Yet here, even this morning, we've heard repeatedly that there are not identifiable rheumatologists that can be attracted into medical centers to establish divisions of rheumatology to, in turn, enhance the curriculum of the medical students, and we've heard several say that they feel that the exposure to medical students in their primary training is just grossly inadequate. How do you feel one could best get what seems to be a proper balance into the picture between the availability of sufficient specialized manpower and, at the same time, not

leave gaps in the primary care physicians who are being trained--in their knowledge?

CLARK: I'm not an expert on this. I have a personal opinion and that is that primary care is best offered by people who are specialists, and, as I said, we don't say anything to anybody that comes into our office about what's wrong with them, or how much money they've got, and if they come in with high blood pressure, we treat that; we treat whatever we find and this is the least expensive way to do this. Our office is right in the middle of a big slum area; it's actually an HMO. But, I think that specialists who are practicing in the community in fields of cardiology, gastroenterology, and rheumatology, which are the family medicine type practices, plus the obstetricians who, strangely enough, give a lot of primary care to people that go to an obstetrician originally--the primary physician should be the person who has the best contact with the patient and in whom they have confidence. I have no objection whatsoever to anybody coming and asking me about any medical problem that they have and neither do any of my partners. There are some specialities that obviously--like a neurosurgeon obviously cannot be a primary physician, but anybody in one of the internal medicine specialities should be able to do a good job of primary care.

DONALDSON: Are there any other questions? Mrs. Carey.

TESTIMONY OF  
JUDITH J. CAREY  
PATIENT

CAREY: I am a 35-year-old housewife, a mother of two sons, aged four and seven. I have had rheumatoid arthritis for 14 years.

Besides the pain and fear of severe crippling, there is the frustration of knowing nobody really knows how to cure you, that you are the object of just so much educated guesswork by physicians likewise frustrated by the disease. They don't know what to do about it either.

Frustration in the arthritic breeds depression. "Am I always going to hurt this badly?" "Doesn't anyone know how to help?" "Am I going to be a burden on my family?" "What good is it to seek medical help? Just more money spent fruitlessly."

So, the arthritic has the potential of being a double-barreled victim, of mental as well as physical crippling. In this former area, at least, I feel the medical profession could do much more.

Since my husband and I married we have lived in four states, and I have seen a dozen or more physicians about my illness. And, as I moved about in each new city, a new doctor would often have a different treatment. In many instances he would, in so many words, tell me the previous doctor didn't really know what he was talking about in prescribing such-and-such treatment and such-and-such medicine. And, I can remember thinking, if one doctor was so wrong by the other doctor's

standards then how can I have any confidence in what the latest one says? And, in time, I didn't.

What bothers me now is that I did not receive any advice on how to live emotionally with my ailment, was directed to no books or treatises on the subject, nothing in the way of coping with it. This is where I feel the medical profession has really fallen down. In time, by reading and research on my own and in conjunction with the Arkansas Chapter of the Arthritis Foundation, I have developed a more positive outlook, and am for the first time learning to cope successfully.

Why can't physicians who are quick to shrug their shoulders when you mention arthritis or, as one or two did, graciously apologize because there was little they could do, at least know enough to recommend books like All Out Against Arthritis by Faye C. Lewis, M.D., or Private World of Pain by Grace Stuart that I have found immensely helpful in gaining emotional balance. No one told me about them. I went to the public library and started looking.

I am fortunate that I am no more severely crippled than I am. The disease has progressed slowly, and at certain times there has been some remission. I have what has been described to me as "classic" notching deformities in the joints of several fingers in both hands, making gripping uncertain at best. I have lost much movement in the wrists of both hands and in my left elbow, which I can no longer straighten out much beyond a 45-degree angle. I usually hang a purse on it so that it is not all that noticeable. At times I am also troubled by pain and swelling in knee and ankle joints and pain in both shoulders. On some mornings I hurt so badly all over that I don't feel worth shooting. I don't walk so well at those times either.

Still, I get around. I drive, do housework, and many who have known me for a long time are surprised when I tell them I have arthritis, despite what to me are obvious outward evidences.

For me, facing the diagnosis was the first step toward coping with the disease. When I first had a doctor diagnose my condition as rheumatoid arthritis, I just went to another doctor. The only person I knew who had it was a childhood friend who was in a wheelchair at the time.

I was a college senior when aches and stiffness I had been blaming on everything else were pinned to rheumatoid arthritis by that first physician. My roommate read up on it and wouldn't even tell me what she had learned.

The second doctor, as I had hoped, dismissed the first diagnosis. But when my hands, hips, and, finally, feet became involved, when the finger joints began to swell, the original diagnosis could not be ignored any longer.

I had rheumatoid arthritis. Once I had it and knew it, I got angry. Why me? There were times I had those old thoughts of why is God punishing me? What have I ever done to deserve this? And, of course, there are no answers to questions like those.



Then with my discouragement through involvement with all those doctors countermanding each other, I went through a period where I would not see a doctor at all. What did they know? More money wasted, more frustration, more depression.

You can't catch anyone's attention about arthritis all that easily. Say polio, heart disease, lung cancer, cerebral palsy, and right away they sit up and take notice. Anyone who has been even remotely connected with those diseases knows what swift and sure killers and cripplers they are. Say arthritis, and someone says, "Oh yeah, my Aunt Cora had arthritis, hands were a little stiff in the morning. Sure won't kill you though."

Maybe not outright, but in its way, over the years, quietly cutting into one's mobility and hope, it can, in its way, be just as destructive.

Say Dr. so-and-so is nearing a breakthrough in multiple sclerosis, and one is impressed. Say so-and-so is deep into organ transplants, and the reaction is the same. But arthritis, oh really? Ho-hum. It just isn't all that exciting.

Maybe arthritis needs an old fashioned publicity agent, like the movie stars used to have: someone to go around and get its name in the papers, dropped into newspaper columns, and mentioned on talk shows; something to get the money for research, slam the board across the mule's head, get their attention.

I have often felt I was shouting in a room full of people, and no one was listening. I am hurting, me and others like me. I have been for 14 years, and, damn it, I want something done. If you can put a man on the moon, you can make me stop hurting.

Money must be raised for research in order to find the cause and cure for arthritis. That is the No. 1 goal. And, as I have said, in the meantime, equip physicians to help patients cope with it, at a mental and emotional level as well as physical.

And, finally, a good word for the Arkansas Chapter of the Arthritis Foundation, easily the most helpful and beneficial of any organization or person I have come in contact with during these 14 years. The educational services and therapy have been the best I have received, and I don't have to pay a penny, although I do make a donation. I'd shake their hands over there except it would hurt my fingers. (A sense of humor is important too.)

DONALDSON: Thank you very much, Mrs. Carey.

[Recording interrupted.]

VOICE: ... sense of humor, but also to realize the problems of the patient in such a way that you have articulated. I think that you will be happy to know that the arthritis team, as part of the Education Committee, is definitely emphasizing not only the physical but the mental and psychological emotional problems of the patient, and I'm sure that we're going to be heard.

DONALDSON: Thank the panelists very much. Would Mr. Roebuck, Mr. Cash, and Mrs. Caplinger come forward? While these panelists are convening, for the record, I would like to enter the receipt of a telegram from Dr. Francis Dalmey, President of the Arkansas State Nursing Association, to the effect that the Arkansas State Nursing Association supports the need for further study and additional funds for the eradication of arthritis...."We offer the Association's support in this endeavor." We appreciate that very much. Mr. Roebuck.

TESTIMONY OF  
BEN E. ROEBUCK  
PATIENT

In the early spring of 1971, I began having real problems with my back and hips. I actually had been having trouble for about 20 years, and had been to an osteopath several times. But I thought it was just "back trouble" and did not realize that it could be a result from a far more serious problem.

But in early 1971, my problems worsened, and I got to the point that I could not put any weight on my right leg because of the pain it caused in my leg and hip and back. I became worse, and I got to the point where I couldn't get around. I could hardly get up out of the bed.

Then I decided to go to a diagnostic clinic for a complete physical examination. I had to wait awhile for an appointment, but about mid-July, I started the examination. They put me through every test--and back again for more. By the time they had finished with all the tests, it was almost two months by the time I had the final consultation with my doctor. He had ruled out everything except spondylitis--which is rheumatoid arthritis of the spine.

First off, the doctor said that the troubles I had been having all these years were probably caused from arthritis. The x-rays showed considerable damage in the area of my spine.

To get me back on my feet, the doctor now prescribed three weeks complete rest--either in bed or up in a chair--but completely off my feet, so that my back and hip could heal.

At this particular time, I had no other pain other than the hip, leg, and, of course, back.

The doctor started me on aspirins, 12 per day--three at each mealtime and three at bedtime. This was the mildest form of medication for arthritis, and that was where he wanted me to start. And it seemed to work real well.

He also advised me to lose 25 lbs. to relieve the strain on my back. He said for me to lay on my stomach at least 15 minutes each day, to keep my back or spine straight. And as soon as I could get around, then started me with the warm-water therapy, which is operated by the Arthritis Foundation at one of the local hospitals.

So I started out on my new routine. The rest for three weeks, along with the aspirins, got me back on my feet. I had to use a cane at first to walk on that right leg, but it gradually got well. And the aspirins seemed to give me the relief that I needed to make me feel better. I lost the 25 lbs. And I started the warm-water therapy and continued it faithfully for about a year.

I would say that it took me about six months to feel that I was back to normal. During this time, I had to really take care of myself, and not over exert or get too tired--or the weakest part of my body (my back) would hurt. I knew that I did not really have the same strength that I used to have. But as long as I got plenty of rest, took the aspirins, stayed with the therapy, I continued to do fairly well.

I went back to the clinic the following year for another complete physical examination--not because I had to see the doctor, but just because I wanted to know the progress I was making. All my tests showed that I was doing well, and normal in my situation.

However, in 1973, two years after I had been diagnosed as having rheumatoid arthritis, I began having trouble again with my hip and back--very much the same as I had back in 1971. I realized that I had not been taking quite as good care of myself, and that I had been working harder and on my feet longer without any rest during the day.

I went back to the clinic and to my doctor, who again prescribed two weeks complete rest so that my back and hip could heal. He kept me on the same medication, aspirins, and said that I could increase them to 16 per day for a few weeks and then go back to 12 when I was feeling better.

I had not been going to the warm-water therapy during the summer, and so I started back as it helps to loosen up all of the joints. At this time I still did not have any pain in any of the other parts of my body--only the back and hips.

I continued doing well through most 1974--I took precaution about getting proper rest and diet. I was feeling so good that I thought I did not need the aspirins, if I just took care of myself. So I began taking less until I was not taking any aspirins. And I stopped taking the therapy. Also, in general, I stopped taking as good care of myself. I worked longer hours, did lot of other things on weekends, and did not take a lot of rest. I thought I was really doing good.

But in early 1975, I began having a new problem. I started having pain in the joints of my hands, wrists, and in my feet. Also, these joints were swelling--which I had not experienced before. And my back began to hurt, just a feeling of exhaustion when I became tired. I started taking the aspirins again, but they did not seem to help that much. Some nights I found it hard to get very much sleep or rest. I just seemed to hurt whether I was doing anything or not. This was something rather new to me.

So I went back to the clinic and to my doctor for another physical examination. From the tests and X-rays you could see the difference and



the wear and tear on my spine in the few years since I had first been x-rayed. Deterioration seemed more apparent this time than at the past examinations.

The doctor decided to change my medication--he put me on Atabrine, one tablet each AM and one in the PM; also, he prescribed Plaquenil, one tablet at noontime each day. With this medication, I have to have my eyes checked every three months because of a possible side-effect. And, I take Mylanta about three times a day to offset the acidity in my system. Of course, the doctor advised me to always get plenty of rest.

So, now I am on new medication, and I know that I must always take care of myself; get plenty of rest--never over-exert to the point of exhaustion. I go to therapy quite often, but have not had to keep a frequent routine with it. But I know it helps me when I go. I try to regulate my work so that I am on my feet a short time, then have awhile when I can sit down. I find that with my condition, it is best if I do not have to stay in any one position for a long time. For instance, driving a car any distance hurts me just as much as walking.

I think the Arthritis Foundation is doing a very good job. I think it is important that they continue diligently with their research to find the cause and cure for this crippling disease.

In the meantime, all who have arthritis must have faith, patience, and hope that they can control their problems until such a cure is found.

DONALDSON: Thank you, Mr. Roebuck. Mr. Cash.

TESTIMONY OF  
CLARENCE CASH  
DEPUTY ATTORNEY GENERAL

CASH: I'm Clarence Cash, Deputy Attorney General. I'm with the Consumer Protection Division of the Attorney General's Office, and some of the people here might wonder what we have to do with this subject we're discussing today. We became involved in this subject because part of our duty is to look at and to police false and misleading advertising in the State of Arkansas, under the Consumer Protection Act passed by the Arkansas Legislature in 1971.

By working with the Arthritis Foundation in this State, we first became aware that there were quite a few products offered and advertised for the treatment of arthritis which were in fact useless. Not only did these products deprive consumers of money uselessly, but often they offered danger to their health. We've worked during the last three years with the Arthritis Foundation to try to police these kinds of offerings and do whatever we could under our authority to remove these kinds of false representations. I've entitled my very brief remarks today, "The Great American Medicine Show."

One hundred years ago, the Medicine Show traveled from town to town to sell potions which would cure any illness. The gypsy, Dr. Good, as Cher

Bono and her famous song told us, represented his product as capable of curing "everything from constipation to corns and cancer - or your money back," which is a typical guarantee.

The Medicine Show is a part of American folklore, and it is considered more famous for its showmanship than its impact on the health of the society it purported to serve.

In these modern times, it is easy to think the medicine show a thing of the past--until, however, you turn on the TV or radio or open a Sunday newspaper supplement, then the Great American Medicine Show comes alive. Only now, it is dressed in new and sophisticated costumes, and I suspect is exposed to many more thousands, if not millions, of persons than the old original medicine show that traveled around in a cart pulled by horses.

Consumers are told that they should buy aspirin, "which contains more of the pain reliever that doctors recommend." Well, what is it that doctors recommend? You can ask your doctor, and he might tell you it's aspirin. So, what that very clever advertising slogan is telling us is that aspirin contains aspirin, and that's something we knew already. Well, that's a very mild form of what I'm going to be talking about, but the stage for the kind of psychology that I'm talking about is set with that kind of--well, maybe not misleading, but certainly, advertising which is useless for giving the consumer the kind of information that consumer might need for making a wise buying choice. Consumers often pay twice as much for the advertised named brand of aspirin than for the product simply called aspirin, which may, in many cases, be just as effective as the advertised named brand. Of course, we now have an aspirin on the market which is marketed in a way that would appeal to persons suffering from arthritis, but which, in fact, may be just plain aspirin and, again, selling for a great deal more than the plain product.

Newspaper, magazine, and direct mail advertisements offer cures for pain and disease which often are surprises to medical scientists. Cancer, heart disease, and arthritis are all subject to quick, easy, but not always inexpensive, cures in these advertisements.

Last year, an advertisement which ran on several local radio stations in Arkansas and which was also offered by direct mail offered a book titled, A Doctor's Proven New Home Cure For Arthritis. The advertisement stated, "You can be cured of this previously incurable disease in your own kitchen on your dining room table at no expense." I don't know how many consumers fell for that kind of advertising gimmick, but I would suspect, if it's like many of the other misleading advertisements, a sizeable number of consumers did order the book.

The Consumer Protection Division sent a letter to the firm demanding some supporting information for the claims in the advertisement. That is the limit of our authority under the Consumer Protection Act, and that may, in fact, be a proper limitation of authority because I am not suggesting censorship, but we do have authority to request or make a demand that we receive some information supporting the kinds of claims made in these advertisements. After accusing our office of interfering



with the freedom of the press and speech, the firm withdrew the advertisements without further challenge, and I suspect because they really could not support the claim.

Another firm known as Medi-Care Company in Mena advertised in this State, "We dare to guarantee: substantial relief or money refunded. Genuine Serial Number Listed: Registered Copper Bracelets."

We received this notice from the Arthritis Foundation, which is very helpful in alerting us to this kind of advertising claim. The Attorney General complained to this company. The company agreed to sign an agreement, a consent order, to cease and desist from such advertising and agreed that no advertisements will be run which misrepresents the effect of copper bracelets upon the cure, relief, or prevention of arthritis, until such time as they could produce some kind of data or information to support those claims, and that in the future they would submit advertising copy concerning representation about arthritis or arthritic cures to the Attorney General for approval. That was over a year ago, and they haven't sent us any advertising claims. I would imagine that this firm has either gone out of business or changed their advertising copy. Apparently, they can sell copper bracelets quite readily without making very many claims if judging from the number of people who wear them is any indication. I have two members of my immediate family who wear copper bracelets, and they don't suffer from anything but an occasional tooth ache. To date we have received no copy to approve, and I assume they are having trouble in their lab providing a product which they can honestly guarantee.

We can, in such instances as the two I have mentioned, take effective steps to stop false cure advertisements. In numerous other cases, we have been unable to legally compel an advertiser to support these claims. Often it is due to the fact that the advertiser is outside the range of our jurisdiction, in another state, or, perhaps, another country, such as Mexico. What we can do, however, even when we are helpless to bring legal action, is to alert and educate consumers to be mindful of the pitfalls that may await them; pitfalls not only that threaten the economic well-being but, more importantly, those that threaten their health.

The old-fashioned medicine shows received more attention from writers and folklore than they did from the public. At the most these drummers of cures were exposed to only a handful of people. But, the modern medicine show, through the medium of advertising, television, radio, and newspaper, gets exposure to nearly all of the people. If you think that figure is too high--that is, nearly all of the people--consider the estimate reported in the 1974 Fall Edition of Arthritis News that "90 percent of the 20 million people with arthritis in this country will fall victims to the peddlers of quack 'cures' at one time or another." That figure is shocking.

To fight the Great American Medicine Show, we are utilizing some of the same means that the deceptive advertiser is using. Each week, our office publishes a column read in some 70 newspapers, called "Consumer Alert." We include in this column warnings of specific bogus cures to alert consumers of the financial and physical danger. These same consumer alerts appear on television in prime time positions donated by several



television stations in the Little Rock market, which covers most of Arkansas.

The key, I think, is consumer education. By warning consumers and suffers of arthritis, as well as other medical problems, repeatedly of these bogus cures or the possibility that cures are bogus, we hope that we increase the sensitivity to the clever and exotic pitch of these deceptive advertisers.

Of course, there are many consumers suffering from arthritis who, even in spite of warnings, will try everything new that comes along in their desperate attempts to find relief. There will continue to be persons defrauded by the Medicine Show, I know. I have no doubt that the show will go on but at least not without someone nipping at its heels. Thank you very much.

DONALDSON: Thank you very much, Mr. Cash. You have emphasized the consumer education aspect of this. I'd like to ask you, from your point of view, are there legal problems--are there deficiencies in the law relating to advertising that contribute to this?

CASH: Primarily, it is difficult to stop an ad before it is placed in some publication, and I would think it would be unrealistic to think that you could ever do that legally because that would be prior censorship. So, I can't think of any constitutional way to stop these kinds of advertisements before they are published. But, certainly, one of the things we want to do is sensitize newspaper editors and classified editors of the dangers that come from these very bogus offerings, and to at least challenge on the front end before the advertisement is published, ask for some supporting data--often if you ask for supporting data that's the last you hear of these people. So that is another tool that we are utilizing.

DONALDSON: By and large, are the media cooperative in this voluntary self-policing, as it were?

CASH: They are very cooperative, but occasionally there will be a very hungry editor who would take any advertisement, because he needs the money, I suppose. It depends on how hungry you are and the size of your newspaper or publication, but, by and large, we've found a great deal of cooperation.

DONALDSON: Are there other questions for Mr. Cash from the Commissioners? Thank you very much, sir. Mrs. Caplinger.

TESTIMONY OF  
ELIZABETH CAPLINGER  
PATIENT

CAPLINGER: My name is Elizabeth Caplinger. I have been a victim of rheumatoid arthritis for 14 years. At the time the disease was diagnosed, my husband was a junior medical student, and I was teaching school. The following year I was forced to take a year's sick leave. At the end of the year's sick leave I still was unable to return to work and had to resign from my teaching position. Since that time my husband and I have adopted two children. It was necessary to have help in caring for my children especially as infants. Since then it has also been necessary to have help in the home to do many household chores.

In the past ten years I have had 12 surgeries, not to mention other hospitalizations for change in medication, rest, and therapy.

As you can see, rheumatoid arthritis has been an expensive disease in many ways. Because of this I can see that some money from the Arthritis Act might be well spent to help alleviate some of these financial difficulties. Naturally, medical expenses are the major drain on the patient and his family. Good insurance for the patient must be available even after the onset of the disease. However, one area that has been most expensive over the years has been that of household help. I would like to see some financial aid or home health aides especially for mothers of young children. An arthritic should not be denied the pleasures of motherhood if she so desires. The prognosis that there might be periods of time that you might not be able to care for young children can be devastating. I speak from personal experience. Perhaps application could be made for financial assistance and reviewed on a regular basis. The patient's physician would need to show that this household help was needed. There are also times following surgery that help is needed even if there are no small children. I had to have live-in help for almost three months at one point, and insurance covered none of this expense. This would also free the spouse or other family members to be more productive outside the home.

I feel that medical research is the most pressing area of need. However, I do not feel qualified to expand on this and will leave that area to persons in the medical field.

I have been fortunate enough to be under the care of a rheumatologist. I have constantly come into contact with others who for various reasons, economic and geographic location included, are under the primary care of a family physician. For this reason, I see a great need for continuing medical education for these doctors, not only in medical management, but as to resources available to the arthritic. I also see a need for more trained rheumatologists.

Thanks to the Arkansas Arthritis Foundation, I have gained invaluable information regarding my disease and ways to cope with it. Doctors just do not have time to go into detailed ramifications of the effects of the disease. I am constantly impressed with how little most arthritics know

about their disease and what can be done to improve their plight. Many give up because of this and are confined to bed or wheelchairs.

Arthritis centers that could reach vast numbers of people would be so helpful. They could offer such things as our local Foundation does, but on a much broader spectrum. Education and assistance in exercise and pool programs, along with self-help devices, can put a person back on his feet. Without this assistance, I would hate to see where I would be at this point. So many day-to-day occurrences, such as turning door knobs, opening jars, sitting on low chairs or commode seats, brushing teeth, and numerous other activities cannot be avoided. It's wonderful to discover that self-help devices are available to help you do these things and become more self-sufficient. For instance, the therapist from the Foundation gave me a small inexpensive device attached to my keys to help me start my car. I would never have thought of this and yet it saves many frustrations. My heart goes out to people I have encountered that don't know what can be done and what is available.

Architects and engineers need to be better trained and more aware of even minor changes that could benefit the arthritic in public and private buildings. Arthritis centers would be doing a service by providing specialized help in building and remodeling plans for the homes of arthritis victims. Many structural changes are minor ones, but most builders and lay people are not aware of these needs.

Engineers need to be more aware of how many ways an arthritic uses his hands and how difficult many pieces of equipment are to operate. My personal pet peeve is push button handles on car doors. I just cannot open them. But, this is just one of many changes that might be made if the designers were more aware of their far-reaching effects.

Another area of need is vocational rehabilitation. At this point, I do not need to work. However, there may be a time that I will need or want to work. I could not return to my original field of elementary teaching and may need help in finding a suitable occupation.

Thank you for seeking effective ways of funding the Arthritis Act. I am hopeful that the areas of greatest concern will be funded as soon as possible.

DONALDSON: Thank you very much, Mrs. Caplinger. A personal response to your car door push button - several patients have told me that they found by carrying a door stop in their purse they can use this as a self-help device that overcomes this particular problem. You might experiment with it if you haven't. Do members of the Commission have specific questions for either Mrs. Caplinger or Mr. Roebuck? If not, thank you very much. Would Dr. Townes and Dr. Tunnell come forward, please? Dr. Townes, please.



TESTIMONY OF  
ALEXANDER S. TOWNES, M.D.  
CHAIRMAN  
MEDICAL AND SCIENTIFIC COMMITTEE  
WEST TENNESSEE CHAPTER  
ARTHRITIS FOUNDATION

TOWNES: I'm Dr. Alexander Townes. I'm currently Chief of the Medical Service at the V. A. Hospital in Memphis, also Professor of Medicine at the University of Tennessee, College for the Health Sciences, and also Chairman of the Medical and Scientific Committee of the West Tennessee Chapter of the Arthritis Foundation.

I appreciate the opportunity to express my views as an individual physician enlisted in the fight against arthritis and as a representative of the Medical and Scientific Committee of the West Tennessee Chapter of the Arthritis Foundation to communicate to you the interest of this group of physicians in the work of this Commission and the National Arthritis Act.

Significant strength exists in Memphis, Tennessee, in caring for patients with arthritis and related diseases and in research and education in this field. Largely as a result of a strong arthritis program at the University of Tennessee over the past decade, which has trained physicians and attracted others including myself to this area, twelve or more rheumatologists are now practicing in Memphis. This city is geographically well situated and well equipped with hospital beds and other facilities as a medical referral center for the Mid-South Region. In addition to the rheumatologists, there are many orthopedists interested in arthritis surgery, and a strong training base in the Campbell Clinic. There is also a school for physical and occupational therapists and for nurse practitioners in the University of Tennessee Center for the Health Sciences.

In addition, important research is being carried out in clinical epidemiology, immunology, and connective tissue biochemistry as they apply to arthritis and related diseases. Training programs in the medical school reach medical students and house staff physicians at all levels as well as post-doctoral fellows training as subspecialists in rheumatology and practicing physicians in continuing education courses.

Despite these strengths, the unmet needs are still great. Reduction in funding of training and research as a result of cutbacks and inflation has imposed restrictions in programs at a time when the impact of the previous years of investment planning and effort is just being felt. Certainly there is a need for increased support for training and research in arthritis and for the development of new methods of facilitating collection of patient data, such as the proposed data bank. We strongly endorse support of these essential activities. However, we would not want to see such support targeted for arthritis subtracted from funds otherwise designated for basic research which must continually be developed for new advances to occur. For example, basic research now being directed toward the problem of arthritis has developed in such diverse fields as tumor immunology, viral host relationships, cellular activation, mediators, and

so on. The progress of the future demands continuation of strong support of basic research as well as application of this knowledge in solving clinical problems.

Despite availability of a strong base of personnel devoted to the care of arthritis patients in Memphis, patient care still falls far short of the existing needs. Patient referrals by physicians are often too long delayed, and close coordination of members of the patient care team is often lacking. Care for indigent or near-indigent patients is woefully inadequate to meet the need.

Development of arthritis centers should help significantly in improving patient care and education in arthritis in the following ways:

- (1) Provide exemplary care for patients with arthritis and related disorders, utilizing the most sophisticated tools available and a team approach to patient management.
- (2) Provide a center for training of physicians and other health professionals to care for arthritis patients.
- (3) Provide a resource center for public and patient education.
- (4) Provide a population base for clinical studies and data collection.
- (5) Provide an outreach of care to underserved areas.

We would visualize the center not as a structure or building but a coordinated consortium of physicians and other health care personnel, laboratories, and research facilities involving the entire professional community and serving patients from a wide area. Centers should be located where there is already established strength in arthritis programs in order to draw upon this in development of innovative programs which will have the greatest impact.

An important part of the center should be its ability to develop satellite facilities in areas now chronically deficient in appropriate care for arthritis patients. We believe that health professionals other than physicians can be trained to provide efficiently some degree of initial screening and referral to the center or to local physicians and to carry out many aspects of continuing care initiated by and periodically reviewed by physicians locally or at the center. A model system for decentralized care in neighborhood clinics for indigent patients already exists in Memphis for many chronic diseases and could be readily expanded to arthritis with appropriate training and funding of personnel. Extension then into rural and other areas could be a logical development of the center to provide care in other underserved areas.

DONALDSON: Thank you, Dr. Townes. Are there questions from Commissioners?

VOICE: I would like to compliment your Dr. Gene Stollerman, who is doing a terrific job as Cochairman of the Educational Committee that I'm

on. I think he has lent some expertise that we really needed, and you certainly have a fine facility there.

TOWNES: I might add that his support has been very instrumental in developing a strong program in arthritis at the University of Tennessee, and it remains strong.

DONALDSON: Dr. Townes, you propose in your definition and description of centers a regional consortium, as it were. Have you given any thought to what might be a workable administrative structure for such a consortium, and under whose aegis it should evolve?

TOWNES: I think this is a very difficult area, and I don't have precise definitions in this. It seems logical that a strong base of this should be a university training kind of environment, but I don't think that any physicians or other personnel involved in the care of arthritis patients and qualified to provide that should be excluded from this. I think one of the areas of concern on the part of some physicians in our own community, for example, is if such a center developed would they be outside of it? I think it should be developed in such a way that all of the manpower available should be included in this and focused on the problem. Exactly how that can be done, I think will need some doing. I think to some extent it could be an administrative structure or a corporation type of structure involving multiple inputs into decisions rather than a single kind of dictatorial authority for the center. There are problems involved in that, I recognize, but I think that to try to exclude any of the resources available would be a mistake.

DONALDSON: The Commission has been interested in addressing this issue as to whether or not the Health Systems Agencies might evolve to be a partial, at least, approach to the problem. Have you given any thought to this in western Tennessee?

TOWNES: I am not familiar enough with what the Health Systems Agency is doing--that is what the Regional Medical Program is evolving into, is that correct?

DONALDSON: Yes. The RMP CHP Hill-Burton now comes under 93-641, and, of course, this is in a developmental phase, but I think attention might well be directed toward it within all these regions at this point because it may provide a structure for approaching some of these issues.

TOWNES: I think where those programs have worked they have been very effective. I have not had a lot of contact with them, and so I don't speak from very much experience. I also have a feeling that they get to be too diffuse and too mal-directed in many instances and have not been, as a whole, very effective. I would hope that the organization that we'd envision would be more directly related to the problem of arthritis and more effectively pointed in that direction, with a little more concentration of effort than I've seen so far in the Regional Medical Program and what might evolve from that.

DONALDSON: Thank you.



VOICE: Dr. Phelps, today we have heard of four very successful groups being listed here today. First we've heard good words about the Arkansas Arthritis Foundation; we've heard about the pediatric clinic in Memphis by Dr. Hanissian; we've heard about Dr. Clark's clinic; and now we hear about Dr. Townes' clinic.

Has the Commission given any thought about going to these places, doing some on the spot study of these people, and using that as a model to advise other people of successful groups? We've had a pretty dim picture pretty well presented today by a number of people, but here we do have four groups that seem to be very successful. We've heard very good things about them, and this answers your question--what group would you use, what would you use as a model? I mean we have some successful groups going now, and wouldn't that be a good idea, to use them as a model?

DONALDSON: Mr. Shields, you want to take that one?

SHIELDS: Yes, I sit with the Community Programs Panel which, of course, is very much concerned as to how to make this work at community levels; we're very much interested in these different kinds of models, and we're very aware that they do exist. One of the best, we felt, was in Vancouver, British Columbia, and one of our meetings was held right at that site so that we could look at, first-hand, what we considered to be a first class model and now try to think how to make it apply in the United States. So, I think that these models are known and have been looked at, as best we can, and, of course, it is not possible to get around and see them all first-hand.

VOICE: Did it fit the description you got of this place when you went there? Did they live up to their standards?

SHIELDS: Yes. They had a few advantages over the United States, perhaps, in being able to control things. For example, one of the problems that we've heard about here is the concern of physicians in one area making more money than a physician in another specialty, and they have been able to deal with that effectively because, basically, their third party payer is one party--the government.

VOICE: Another problem that we all have to think about is this. Now, we've heard a great deal about money; as a matter of fact your panel has said that we as people can help you by contacting the right people in Washington when this problem comes up, but now you're faced with this other problem that once you start providing us with the money, you start writing the rules. Now, I don't know if these people are willing to accept the rules that some of you people are willing to put out. I mean, this is the second problem. How do we prevent the person who handles the money from writing the rules that might be contrary to what the people who are trying to do the job find is pleasant for them to work under? So, that's another thought we have to give. The rules will have to be in keeping with the American standards of private enterprise.

VOICE: That's one of the hazards, Dr. (inaudible), if one sets up a model, then whatever model one happens to pick becomes the pattern, and a

lot of people may not fit. That's why we have shoe stores with rows and rows of shoes, because not everybody wears size--whatever.

DONALDSON: Precisely. I think that one of the things that the Commission has become aware of is a great need for flexibility and pluralism in addressing these issues. It's fine to project models, but it becomes very sticky if they tend to become standards, and I would assure you that the Commission is highly aware of this potential.

VOICE: May I make a comment, too?

DONALDSON: Yes, sir.

VOICE: I have not a thing against universities, I think they're superb. But, if we talk about the university main centers instead of a university-associated center, I think then we're going to start with the attitude of the university for the patient. The attitude of the university towards a private patient is entirely different, this whole clinic. We're dealing here with people who come back (inaudible).

VOICE: As a former faculty member in a medical school, sir, I would argue that not all universities are cold and calculating towards their patients. They do have particular approaches to patients because their primary purpose is the teaching of medicine, but it is slightly different than what you stated.

VOICE: I would like to agree with him that we mustn't always think it's the third leg of the stool. I mean, you have the teaching, the education, the research, and then patient care. Many of these organizations tend to go away.

If you look at your program, you're pretty well balanced, which is fascinating--it is rarely that you see a balanced program where you have a number of private clinical things. But I would like to emphasize the same point: don't give up on the clinician. Make sure he's got his right role in everything that you do, it is an expense of the medical schools, I mean taking over what the clinician cannot do. The reason the clinicians are usually not at these meetings is because they are too busy taking care of the patients. That's the unfortunate part about it. But, luckily, today you have a number of clinicians. I am very happy to see that.

DONALDSON: I think what has surfaced in this informal discussion is rediscovery of a continuing town-gown problem. This has been ongoing and recognized for a long period of time. With this restructuring that is occurring, and I think that this is one of the things this Commission is all about, and certainly one of the things that Public Law 93-641 is all about is an effort to try to break down and breach some of those dichotomies that have developed and to get both groups, if you would, back into the realm of practicality and what really goes on and hopefully working together and constructively rather than as adversaries. I suspect from the response to the question that there are concerns about the administrative structuring of any center's role that may emerge, and I can assure you that the Commission will give a lot of attention to this. Dr. Tunnell.



TESTIMONY OF  
E. TRAVIS TUNNELL, JR., Ph.D.  
CLINICAL PSYCHOLOGIST  
ARKANSAS PSYCHIATRIC CLINIC

I am Dr. B. Travis Tunnell, Jr., a clinical psychologist with the Arkansas Psychiatric Clinic, a member of the Board of Directors of the Arkansas chapter of the Arthritis Foundation, and I have had rheumatoid arthritis for six years. In my testimony before the Commission, I would like to discuss the psychological aspects of pain in arthritics and how it affects their lives. I will also propose how Federal funds could be used to research effects of this pain and how those effects might be alleviated or lessened.

Pain is possibly one of our most serious disabling diseases. Its cost in terms of medical expense dollars has been estimated at 25 billion dollars a year. When pain becomes a way of life, and the patient spends most of his day lying in bed, the physician can be plagued by unending demands. The patient is often bent on proving he can't be helped or on getting medication he now abuses. The doctor-patient relationship is strained to the breaking point. Many doctors do not think of pain as a specific entity, but as a symptom. There is evidence to indicate that this is not the case. Pain may exist of and for itself. New research suggests something different about pain, undercutting the common conception that it is a symptom, no more. While this is frequently true, thousands of people suffer from chronic, disabling pain with no justifiable pathology to account for it. Much of this research has been accomplished by Dr. John J. Bonica, an anesthesiologist at Seattle's University of Washington. Dr. Bonica started the first pain clinic 25 years ago and established a multi-disciplinary clinic.

Dr. Bonica reports that patients have come into the clinic who have had as many as 42 operations for low back pain, with no improvement. Nerves have been cut, vertebrae have been fused, but the pain has continued. The assumption underlying this type of surgical procedure is that if you block the nerve pathways, that pain will be interrupted. Too frequently the pain continues.

It has been assumed in a general way that any injury damages tissue, and that this affects special receptors in the skin from whence the message of tissue damage travels along nerve pathways to a pain center in the brain. However, this is not always the case. Consider, if you will, the Indian fakir who plays hopscotch barefoot on a bed of fiery coals with no evidence of anguish. What messages travel along his nerve pathways from foot to brain, and how does he interpret them - as pain or as something else?

How much, then, of the reaction to pain is related to cultural background and conditioning? Can it affect one's perception of pain? Distraction or its opposite, concentration, is also another factor. In many instances an individual has received physical injury, and yet, due to distraction or concentration, is unaware of the injury. Conditioning, distraction, or concentration all have one thing in common in that they illuminate the puzzling fact that even where a direct physiological injury



is involved, pain is not necessarily a simple cause and effect phenomenon. It seems that the closer pain is examined, the more it becomes a mystery.

Socially, we tend to reserve the word "pain" for things that are related to tissue damage, thus, correlating tissue damage with pain. But, there is no necessary cause and effect relationship. Pain is said to exist when the individual complains of it. We are unable to cut into the body or the brain or into the skin and find pain. Pain is an altogether private experience.

Pain research amassed by Dr. Bonica in his clinic has been aimed primarily at pain control, origins of pain, and the theories underlying the description and/or explanation of pain. But what about the arthritic who suffers from chronic pain? Today doctors tell us that the pain can be alleviated, however, if you discuss this with a person who has this disease, 99 percent of them will state that they continue to hurt. Even in the forms of arthritis where there is no visible tissue damage, pain still exists. Certainly this type of pain cannot be separated from emotion.

The individual who suffers from chronic arthritis frequently shows signs of the depressed personality, being introspective, self-punishing, accident prone, or, possibly, hypochondriacal. The unpleasant fact is that many such people build for themselves a small universe enclosing their pain and a behavior pattern that victimizes family, friends, and even their physicians.

You may ask, how does this happen? When the environment rewards a behavior pattern, the chances that this behavior will be repeated are increased. So pain behavior tends to perpetuate itself.

The arthritic patient who finds that his or her pain brings new attention from a loved one who has otherwise been indifferent toward them, finds this attention to be very attractive, even though it is contingent upon their continuing to hurt. There is no conscious maliciousness involved, only the consequence that the pain behavior has been reinforced by a pattern of reward. This is only one example of how pain behavior tends to perpetuate itself.

Man is a social creature, needing identity in relationships to prevent a sense of isolation and alienation. If the individual's role in society fails to provide this sense of social identity, the role of the chronic invalid may offer an alternative.

In short, pain is very complex. It may be a warning of disease, a bid for attention or sympathy, a signal of unhappiness or depression, or merely a characteristic way of reacting to other people. Whatever it is, it presents a puzzle to the physician who is called upon to do something about it.

Given unlimited funds, research directed at the pain that the arthritic suffers might be accomplished in the following areas: (1) The use of bio feedback. This is a technique that has had considerable success with individuals suffering from migraine headaches. (2) The use

of group or individual supportive psychotherapy with arthritic patients. (3) Deep muscle relaxation and/or hypnosis. It is a known fact that when a person is tense, the pain that they suffer is exaggerated. (4) The training of professional and para-professional personnel in dealing with "the hurt" that the arthritic suffers.

Thank you for your concern and time and for the opportunity to present this testimony.

DONALDSON: Thank you, Dr. Tunnell. Are there questions?

JENERICK: I'm not sure whether it's a question or a comment. I heard somewhere that the pain that's easiest to bear is the pain of others, and I think your statement goes to that, that pain is a very personal thing, a very real thing. I've been involved through some of my other work at the National Institutes of Health, in a pain-related subject; namely, evaluation of the use of acupuncture. This started several years ago, and, amazingly, after several years of study it's still impossible to say how well acupuncture works. In the meantime, I think it's proving itself clinically to be kind of a bust. But, in the process of this program devoted to the study of acupuncture, we had occasion to assemble a number of people, including Dr. Bonica from Seattle, who was chairman of our study group, and if acupuncture had any real effect for the American people I think its effect was that it caused specific attention to be directed at the subject of pain itself. As a consequence, within the past few years among all of the individual programs the National Institutes of Health is involved in--ranging all the way from sickle cell anemia and of course, a very large cancer program, and heart, arthritis, on on, and on--pain really had never in the past been identified as a specific problem area for the nation's public, although your figures are quite right. It's a staggering cost, and it affects a staggering number of people. Within the past few years, as I said, the National Institute of Dental Research, because of the organizational limitations established by the law, has turned specifically to actively encourage and support research in dental pain. (If you're like me, this happens to you all too frequently, each year.) In our own institute, the Institute of General Medical Science, this is part of a program in trauma which Dr. Gay was a principal in establishing. Trauma accidents are certainly associated with pain. Again, a specific program is underway. Funds are being earmarked for this research. The Institute of Neurologic Diseases and Stroke has, under other titles, supported a lot of research devoted to pain, and the advantage is that pain has been studied for sometime with a lot of attention. The disadvantage is that there was never any proper attention given to it. I think we see that here; arthritis has been with us for a long time but there's never really been any kind of national awareness of an arthritis problem.

VOICE: In your acupuncture study, did you say you could use electrical stimulation of the needles?

VOICE: Yes, sir.

VOICE: Could I add a footnote to what Howard said? I encountered John Bonica in a hotel about four weeks ago. He was walking with a cane, and I

said "What's wrong?" He said, "I've had an osteotomy in my hip; I have arthritis." I said "Well, you know, perhaps you'd like to talk with the Commission sometime." So, we're hoping that we'll hear from John.

DONALDSON: Thank you, gentlemen, very much for your testimony. Would Dr. Janechi, Dr. Nelson, and Mr. Satterfield come forward please? Would you proceed, sir?

TESTIMONY OF  
CARL NELSON, M.D.  
CHAIRMAN, DEPARTMENT OF ORTHOPEDIC SURGERY  
UNIVERSITY OF ARKANSAS  
CAMPUS FOR MEDICAL SCIENCES

NELSON: I'm Carl Nelson, Professor and Chairman for the Department of Orthopedic Surgery at the University of Arkansas, Campus for Medical Science. I'm here representing the Department of Orthopedic Surgery. I have also been asked by the Chamber of Commerce to come and speak, and I'm representing some of my strong personal views as well.

It is suggested that musculoskeletal arthritis institutes be established to give idealized care to patients, to study the causes and treatment of arthritis, and to educate those associated with the care of arthritic patients, as well as the patients themselves.

These centers would provide a concentration of talent that would be structured to include rheumatologists, primary care physicians, orthopedists, musculoskeletal research personnel, physiotherapists, staticians, social workers, etc.

These centers would provide not only excellence in care, but would probe the basic research problems of arthritis and present to physicians a model method of dealing with arthritic patients. In this way, research, training, treatment, education, and the public needs would be most efficiently and most readily solved.

We feel strongly, too, that the direction of funding should be clearly allocated to the patient needs and perhaps not as much to the organizational physician's needs. Eastern centers, in Harvard and most places, will continue to do very well and promise very good things for us. But, we need centers in Arkansas. We must be able to deliver and improve care, and it must be freely accessible for patients in this area from every socioeconomic part of life. We feel that's a very critical portion for us.

I must comment, too, to the so-called town-gown relationship. In our orthopedic community we have some of the finest, most compassionate orthopedists in the country in private practice. We also have those in the university practice as well. All being physicians, it's just a matter of where you might be. We certainly have people in the community who could be professors as well, and I think we have no argument with the private practitioner or with the university physician. Our energies should not be delegated to that but to what is really wanted by the



patient and that's the care of the patient. I apologize for my philosophical bent on that comment.

DONALDSON: No apologies necessary for that.

NELSON: Thank you.

DONALDSON: Thank you, Dr. Nelson. Are there any questions for Dr. Nelson?

VOICE: We hear from so few orthopedists that I'd like to have you expand upon what you see as the role of the orthopedist as it's represented within the confines of the provisions of the Act.

NELSON: I think he should be an active participant and, if you would like my personal ideal, a co-holding leader with the rheumatologist--that you'd set up a structured program in which the orthopedist could train not only his orthopedic residents further in the care of arthritis but to train the students and to offer to the practice community a place that they would come and take part as well. Not a university-structured, but a physician-structured orientation with the orthopedist, the rheumatologist, and the primary care physician working at this at one central area. We all know very clearly that the way to really get things done is get everyone together who's interested in the area and put it together and to work at it in this fashion, and the orthopedist is an integral part of this. As you know, my interest for seven years has been arthritis, and the majority of the people we have on our staff now have an arthritic bent. So, we're quite concerned about this development; we feel we should play a role, but a part of the role. I spoke last night at Camden, and one of the local physicians pointed out that one of the needs is patient education. There are patients in some areas of many states who really have little idea as to what the facilities are or what can be done for them. So again, education, research, patient care, and organization--and, I think if you can put those all together we'll see some of the things that we all want: finding what the causes of arthritis are, or at least some of the causes, especially in rheumatoid arthritis; improved and better care; analysis of really what we do; and the delivery of care of the patient improved throughout the State for every person, no matter what their socioeconomic background might be.

DONALDSON: Mr. Satterfield.

TESTIMONY OF  
W. W. SATTERFIELD  
PRESIDENT  
POWELL & SATTERFIELD, INC.

SATTERFIELD: I have been interested in the problem of arthritis and have been involved in the fight against arthritis for several years. Two members of my family have been afflicted by the disease, one with rheumatoid arthritis and one with juvenile rheumatoid arthritis. I have seen firsthand what damage the disease can do in terms of pain and suffering, as well as economic, social, and psychological problems. I am familiar with the problem of arthritis as a personal tragedy as well as a public health problem. Having been active as a layman volunteer in the Arthritis Foundation for more than ten years and having served at the chapter, regional, and national level within that organization, I am familiar with the various programs in our nation designed to fight arthritis through both governmental and voluntary agency programs.

The National Arthritis Act of 1974 accurately describes the problem which arthritis poses for our country, and it offers hope for an effective national policy to solve this problem. The obvious needs today in the fight against arthritis are research, education, and patient care.

Research must be conducted to find better ways to care for arthritis patients, as well as finding the cause and, ultimately, a cure for the disease.

Education of arthritis patients is essential in order that they may know to seek and demand the help that is available to them. Education of the general public as to the social and economic problems resulting from arthritis is important, as is the continuing education of the medical profession as to the current methods of diagnosis and treatment which are available.

There is a great need to continue improving the diagnosis and treatment of arthritis and to improve the delivery of this care to the many arthritics who are either undiagnosed or, even though diagnosed, are receiving inadequate and, in some cases, incorrect treatment.

There are various programs in existence today to try to meet these needs. These programs are carried on by a combination of medical schools, hospitals, State and Federal government agencies, and the Arthritis Foundation. While progress has been made in each of these areas, it is being made at a rate much too slow in view of the enormity of the problem and the number of people afflicted by the disease.

In determining a Federal government program to fight arthritis, obviously all areas of need (research, education, and care) deserve money and manpower. Because we have limited resources, our money and manpower must be allocated wisely and must be invested where it will have the greatest immediate impact. It is my opinion that the emphasis of the Federal program should be in the area of basic medical research and training of medical personnel. Regardless of the advances made in recent years in the areas of drug therapy, physical therapy, and orthopedic

surgery, the only real hope for the arthritic is the eventual discovery of the cause and cure for all types of this disease. We are at a point where interest in the field of rheumatology among newly graduated physicians and medical researchers is at an all-time high while, at the same time, funds available for training are decreasing. The budgets of existing arthritis centers and medical schools are inadequate for proper research and training activities, and the Arthritis Foundation has had only limited success in raising funds in an amount sufficient to have a real impact on the needs in research and training.

We need to adequately support those who are qualified to conduct medical research. We need to train new research personnel as well as train teachers, practicing rheumatologists, and general practitioners. In my opinion, the order of priority for a national plan should be:

basic medical research;

training of rheumatologists for research and teaching;

training of rheumatologists for private practice;

medical school programs for adequate rheumatology training for general practitioners.

As to the best means for accomplishing these goals, it appears that the present system of arthritis centers and the program for competitive grants for postgraduate fellows is a good one. I have confidence in the medical professionals in the National Institutes of Health and in the American Rheumatism Association and would rely upon their judgment as to the best system for organizing this medical program and funding it.

There is an urgent need for the Federal Government to provide support of research and training programs if we are to conquer arthritis. To not meet that immediate need through positive Federal action would be a definite failure of the Government in fulfilling its responsibility to seek solutions to this major national health problem.

In closing, I would like to say that as an Arkansan, and, speaking for our surrounding sister states, we welcome you to our area; we appreciate you being here; we're flattered that you chose Little Rock as the site for one of your hearings; and we regret that your stay here is so brief. As an arthritis volunteer and speaking for those who are active in the fight against arthritis, we appreciate the challenge which you individually have accepted in serving on this Commission. We wish you well in your task, and, after observing the hearing this morning, I would have to say that we admire your physical endurance as much as your dedication. Thank you.

DONALDSON: Thank you, Mr. Satterfield. Are there comments or questions from the Commissioners? If not, in concluding I would like to thank each of the witnesses particularly for the obvious great detail of thought and time that they have put forth in making their presentations and in formulating them.



I think that they have in their various ways touched upon almost all of the major issues that we find confronting us, and I wish to assure you that the Commission is going to do its utmost to try to represent your views and to do it in a logical method in its presentation to the Congress. I think I can also speak for the Commissioners individually in commending the Arkansas Chapter of the Arthritis Foundation for its ongoing effort. The testimony this morning, I think, is quite impressive in regard to its accomplishments of the dedicated individuals who are working with, it and I particularly am impressed with the continuity of effort. I hope that we can in some way transfer this need for continuity in all of these levels that Mr. Satterfield summarized so beautifully relating to research, education, and patient care in a meaningful way to the Congress. Thank you very much for your attendance and participation. Yes, sir?

VOICE: Mr. Chairman, I've talked to the members of the audience, and I think we would like to say this was a most excellent hearing. You certainly should be cited for it. I've been at a number of hearings, and this is one of the best conducted I've ever been at. There are two things that I was interested in that haven't been discussed, and I hope that they will be discussed at other meetings that you have. One is housing for the arthritic. Not just public housing, but independent, separate unit type of housing that they could afford and live in--retired arthritics, for instance. And, the other, I noticed that you did not have a physiatrist, or a medical specialist in physical rehabilitation, here today, and I think we should hear if they have something to say on arthritis.

DONALDSON: In some of the earlier meetings there have been excellent representations from physiatry and from physical therapy, so I don't believe that the Commission exposure has been void. I think that there has been a gap in housing considerations, and we will certainly endeavor to see if this cannot be included on a future agenda.

We thank you very much, and we stand adjourned.

S U B M I T T E D S T A T E M E N T S

MERLE C. ANSLEY, C.R.N.A.  
Little Rock, Arkansas

November 3, 1975

I have a very personal interest in the National Arthritis Act which was passed in Congress and signed by the President, January 4, 1975.

I am a Certified Registered Nurse Anesthetist, working in my profession since 1942. Early in 1973 I became totally disabled due to a diagnosis of traumatic arthritis, affecting my fingers, hands, cervical spine and back region, preventing my return to work.

Economically it has hurt drastically with inflation fast depleting my savings. Mentally and physically I am adjusting with the help of a very knowledgeable rheumatologist, Dr. S. William Ross, and the Arkansas Arthritis Foundation, who are providing an excellent program of physical therapy exercises in a heated pool.

I am one of the few fortunate ones due to the above interested people, but the thousands of others who are told "arthritis is just something you will have to live with" are very discouraging words.

Being in the medical profession and daily contact with this crippling disease, I would like to see the appropriation used in the following: 1. clinical research; 2. training physicians and allied help; 3. treatment and rehabilitation.

Thank you for your help and understanding.

DELORES BARLOW, M.S.N., R.N.  
Jackson, Mississippi

October 30, 1975

I am extremely interested in the development of long-range arthritis plans currently being discussed in our Congress. My interest stems from being a member of a family where a female member has severe arthritis, and as a nurse currently associated with a rehabilitation facility in Jackson, Mississippi.

My personal exposure to arthritis goes back several years. This exposure was the result of my contact with an aunt and her mother who was completely bedridden with severe arthritis. She was affected in several vital organs, and lived with constant pain. The disease process precipitated not only pain, but severe contractures and joint destruction. She was totally dependent on others for assistance in daily living activities and hygiene. Although medical knowledge and practice has progressed considerably since this very astute, previously very active lady was diagnosed and finally consumed by the disease, we are still faced with the ravages of arthritis. Her daughter is now fighting every day to avoid being bedridden and dependent as the result of the disease process.

We need many millions of dollars to aid in finding answers and, hopefully, a cure for this terribly debilitating disease process.

As a result of her arthritis, my aunt has had at least three surgical procedures, and is now facing a fourth. As a result of this severely crippling disease, my aunt has found herself losing work, yet still trying to be a productive member of society. She is totally dependent on her income as a secretary for the Home Demonstration Agency in her home town of Greenwood, Mississippi. She relies upon this income and her hospitalization insurance to take care of her health care needs. She has elected not to try and utilize other outside economical resources as long as she is able to take care of her needs on her own. As the disease progresses, she finds her primary source of income power (her hands for typing, filing, et cetera) becoming increasingly more involved, painful, and limiting to her. Now her means of ambulation, her feet and knees, are becoming a severely limiting, painful focus for her disease. She is unable to sit down in the bathtub for fear of being unable to get out. Needless to say, every day is a challenge just to get up, work, and to function in activities of daily living.

Presently, in Mississippi, we have only one rehabilitation facility for working with the victims of arthritis, and it has a limited bed capacity. The comprehensive therapy available is so vitally needed, but yet severely lacking because of space and funds. Regardless of physical facilities, we are also faced with a severe deficiency of not only rheumatologists, but physicians well versed in diagnosis and treatment of arthritis. Comprehensive medical provisions are sorely needed. These provisions may be met through formal medical school programs as well as ongoing comprehensive educational programs on a statewide basis.

As a part of a comprehensive program for arthritis patients, we need allied health professionals. These professionals need not only well-grounded education, but ongoing educational programs to insure that their knowledge is kept current.

Granted, cancer and heart disease are crippling, death-insuring diseases, but arthritis is a very painful, body-involved process that deserves Congressional interest. Money for research, care, and education are desperately needed. This crippling, painful killer is just as much a reality as cancer. It is a disease that has no regard for age, yet has extremely long-term consequences not necessarily culminating in vital system death, but, more horribly, in constant pain, functional limitation, and severe psychological stress. I implore you to actively solicit and support Congressional action for highly wonied arthritis plans.



ARMINTA BERRY  
Little Rock, Arkansas

November 5, 1975

The Arkansas Arthritis Foundation has an excellent program of physical therapy exercises in a heated pool which has been very helpful to those using it.

Having arthritis, I would like to see a plan utilized for more services of this sort (treatment and rehabilitation) for arthritis and related diseases, and more clinical research carried out.

JOHN H. BOWKER, M.D.  
Little Rock, Arkansas

November 12, 1975

As an orthopedic surgeon, for the past ten years I have seen a majority of juvenile rheumatoid arthritis patients cared for under the Crippled Children's Unit of the Arkansas Department of Social and Rehabilitative Services. Upon reaching the age 21, most have moved to adult care programs being largely lost to effective follow-up so far as the JRA Clinic is concerned. Follow-up through age 21 has been fairly good, but not of registry quality. Multiple pediatricians have been in attendance over the years, varying in special knowledge and availability. We have had physical therapy available, but no occupational therapy.

Those program elements we need to develop, in my opinion, are:

- (1) A statewide registry of juvenile rheumatoid arthritis patients, including those treated both privately and publicly. This will permit adequate identification and follow-up of juvenile rheumatoid arthritis cases throughout life, in order to improve care by increasing our knowledge of both the natural history and response to various treatment regimes of this less than common disease.
- (2) A true multiple-discipline clinic team to consist of:
  - a. Pediatric Rheumatologist
  - b. Orthopedic Surgeon
  - c. Physical Therapist
  - d. Occupational Therapist
  - e. Nurse Practitioner
  - f. Social Worker
  - g. Psychologist

- (3) A regularly held clinic at Arkansas Children's Hospital staffed by the above team. The full team would see both state-sponsored and private patients referred to it on an equal basis.
- (4) The addition of an occupational therapist to the statewide home care program currently sponsored by the Arthritis Foundation, to serve both children and adults.

Currently, funds are needed for:

- (1) Special training for a three- to six-month period in pediatric rheumatology for a qualified pediatrician interested in this specialty.
- (2) Support of a JRA registry, including registrar's salary.
- (3) Support of team members for special training, salary, research, etc.

SIDNEY A. BROWN  
Little Rock, Arkansas

November 12, 1975

Some fifteen years ago I began to have a lot of pain in my feet. I began to seek medical help with my problem and went from one doctor to another for about three years. During this period my problem was diagnosed as gout, rheumatism, and various other ailments, and all the while my problem was getting worse.

Finally, I went to Dr. Ross at the Little Rock Diagnostic Clinic, and he diagnosed my problem as rheumatoid arthritis and began treatment. I started to improve, and I believe the disease is arrested now as well as can be expected. The problem is the disease left me crippled. I have had surgery on both hands, and my feet are all warped around, and I just can't seem to get the proper shoes to help me make it without so much pain. I have spent hundreds of dollars on special shoes and supports and pads, and, of course, each time I seem to improve, but I guess there is no way to get rid of this pain.

My occupation compounds my problem. I have a service station, and all that concrete and bad feet just do not make a good combination. But it is pretty hard to walk off and leave a business that you have been working at and building for thirty years, especially when there is no place for a worn-out service station man to go.

Naturally, you can see what this would do for a person's life. It has altered both my business and family life because I just simply cannot do all the things I have done in the past. Most certainly I cannot do anything of a physical nature in a hurry. All my movements now are slow and easy and deliberate. I can still get the job done, but not as easily nor as quickly as in the past. This puts an added burden on life, emotionally, physically, and financially.

The financial burden is a really tough one. The doctor bills and medical bills are very expensive, and, of course, they never seem to end. The therapy treatments are expensive and time-consuming. And, as I wrote earlier, all of these special shoes, appliances, and equipment that I have tried and still use are expensive.

I really don't know what course of action should be taken as far as the Government is concerned. I think that an educational program to help a person who thinks he may have arthritis to determine if he does have it, without having to go the route I took, would be good. In other words, let people who have the symptoms know what is available and where to find out if they actually do have arthritis so that if they do, they can get started on a treatment before they become crippled.

For the people that have arthritis, it would be a big help if we had available in our community the facilities for therapy, such as whirlpool baths, steam baths, paraffin baths, and exercise equipment. These things are available now, but, as I said before, they are usually quite a distance and mostly pretty expensive.

I hope in some small way this will help you in formulating a plan to help the arthritics.

MARY ELLEN CORWIN  
Benton, Arkansas

October 29, 1975

I am 50 years of age, and have been treated for a rheumatoid-type disease for the past 16 years. I was treated by rheumatologists at Cleveland Clinic, Cleveland, Ohio, from 1959 to 1965. We moved to Arkansas in 1965. I became totally disabled five years ago, at which time my disease was finally diagnosed by Dr. Eleanor Lipsmeyer, rheumatologist, and Associate Professor of Medicine at University of Arkansas Medical Center at Little Rock. I have been under her care ever since. I have been grateful to have had such an excellent doctor caring for me.

She diagnosed my disease as a rare form of rheumatic vascular disease called "polymyalgia rheumatica cranial arteritis." This disease affects my whole body. I am in constant pain and have high sedimentation rate. The treatment has been Prednisone (steroid) for the entire five years, dosage varying somewhat as to S.R. and various other factors. Treatment has also included many medications to counteract toxic effects of the Prednisone, which have included ulcers-perforation, pancreatitis, osteoporosis, multiple fractured ribs, almost all vertebrae collapsed, and, six months ago, T-12 vertebrae broke, making me bedfast on my back since then. In addition, about one and a half years ago, I developed lytic bone disease (lesions in skull, knees, etc.). The doctors have been unable to explain this development after numerous tests.

The past six months since I have been bedfast, I've required nursing care. My husband is 76, in poor health, and has been unable to care for me. For this reason we have had to hire live-in day help, any help we could get to care for me. We found it impossible to get competent, honest, dependable help even though we had to pay between \$300 to \$400 per



month, and in some cases this included board and room in addition. Some of the help we got came to us with good references and turned out to be outpatients from the state hospitals. You can imagine the problems, grief, and hardships we endured as a result.

I collect Social Security disability of \$130 month. My husband draws Social Security and Railroad Retirement, making our combined income \$600 month. For the past six months, we have been forced to pay out over two-thirds of our income for care, in addition to our insurances and medical supplies, etc. Medicare helps cover some of my expenses, but has not covered any of my home care, nor will it cover any of my nursing home care cost. I have Medicare and Blue Cross nursing home coverage, but I would have to be hospitalized for an acute condition before I could file a claim for Medicare. And then they class mine as custodial care, but when I entered the nursing home I was classed as requiring skilled nursing care.

I had a most unpleasant experience in a nursing home for four days six months ago, and so we were reluctant to go this route again. But in desperation, because I had no one to care for me and my husband is entering hospital next week for artery blockage surgery, I was forced to enter this nursing home on October 23, 1975. This care will cost around \$450 per month. (I am only explaining to you the cost of my care alone as it pertains to arthritis federal funding, and in no way includes my husband's medical expenses.) In addition, we have the expense of maintaining expenses for our mobile home for my husband, food, insurance, utilities, rent, etc. In other words, our expenses are far exceeding our income and have for past six months.

I am sure many other arthritic patients are placed in same impossible financial position that we are. We are willing to pay as much as we possibly can to help, but I would like to see Federal funds made available to help pay for care, for nursing care in the home, if possible, or for care in nursing home, if necessary. I would like to see this care made available to patients, without two miles of red tape involved, based on their expenses as related to their income.

I am receiving excellent care here and highly recommend this facility; however, I'm greatly concerned as to how long I am going to be able to stay as our meager savings are dwindling fast at the rate we have been paying for past six months and continuing more now. There is no way for us. I'm praying that the GOOD LORD will see us through somehow. My doctor said I will require permanent care.

I would like to encourage arthritis patients on their demise to donate their bodies (for which I have made arrangements) for research. If the Federal Government would allot sufficient funds for research, such as they did years ago for polio, maybe thiscrippler can be eliminated in time, too.

Our local Little Rock Chapter of Arthritis Foundation has been most helpful to loan me equipment. I would like to see Federal funds supporting these groups so that they can loan needed aids to patients who cannot afford them.

This has been a long, detailed picture of how this disease has affected our family. I'm sure this same story has been faced by thousands of others. God bless you all for your concern and interest in our views.

Have a nice day!

P.S. I hope this is legible enough to be typed. I've tried to write in almost a lying position with limited use of hands.

Thank you.

MARY ELIZABETH DIDEN  
Pine Bluff, Arkansas

October 28, 1975

"We don't know why it flares up....and we don't know why it goes into remission...." How that statement must cut into the heart of a physician - how he must have to fight the frustration and helplessness he is made to feel by a disease that eludes his efforts to help and heal!

"But we do know that if you will do this...and this...and be vigilant in your daily fight, at this stage you do not have to be a cripple." What a ray of light to one sitting in a wheelchair, to one who felt that life each day was like climbing a slippery hill, only to struggle and fall back below the point where the day began!

I am sure I am not the only one who has heard these words from a wonderful physician who has dedicated his life to helping fight this monster, "A," but it has seemed to me over the last few years that not all patients are willing to make this fight, not all seem willing to accept their part of the responsibility for doing what they can. Why? Perhaps it is cynicism, perhaps it is disbelief, perhaps it is part of this terrible illness that it numbs the fight in our spirits. But I do know we in Arkansas are so extremely fortunate to have the Leo N. Levi Hospital (located in that heavenly endowed Hot Springs), we have so many other fine facilities staffed by trained doctors and therapists who work so hard to do all they can to alleviate some of the suffering of those poor souls who come to them....And then we have those that will not accept and use what is offered to them.

This is the very fact that prompted my letter. I am not qualified to speak regarding the distribution of funds provided to help this problem, but I do sincerely hope that serious thought will be given by everyone in directing aid toward the very source. We already know a great deal about helping those afflicted (if they will help themselves), could we not now help the doctors and scientists who alone can put the words in the mouths of the physicians that can replace, "We don't know why....We don't know when...."

As a RA in remission, and thankful each day, I pledge to do what I've been told, maintain the vigilance instilled in me by a marvelous doctor and therapist, and hope that the research and laboratory work will have Godspeed and all the help we can muster toward finding the WHY'S.

FREDA J. FRYE

I live alone, and I realized that each day, household tasks that were simple became more difficult to perform, due to weakness, inability to climb, to stand, and to stoop. My coordination was poor, and I occasionally dropped articles. At times it was difficult to dress.

As my arthritis progressed, my social life began to slacken. Driving became difficult, especially backing. One by one I eliminated Business and Professional Women's Club, Eastern Star, and Kappa Kappa Iota. Male friends no longer asked me out or dropped me. Finally church activities were dropped.

Pain, stiffness, isolation, and desperation were surrounding me. My personality suffered. I needed more and more rest.

My knees buckled, and I became knock-kneed. I began using a cane.

As I dressed to go to work each day, I'd have to rest, so it became necessary to arise at 5:15 each morning.

Typing became difficult, due to swollen hands; files were difficult to reach, which necessitated stooping. Pulling the check protector handle was so painful, I did a few daily.

My eyes were affected, they felt dry and irritated. Reading fine print was difficult. My employer stated that I could do my work faster if I could get around faster. I finally terminated to have surgery on both knees.

The need for better physical therapy facilities is so great that perhaps if I had had the proper treatment, I would not have become inconvenienced. My doctor was so concerned he told me he could not sleep for thinking of my condition.

The average person, as well as the afflicted, is indifferent to arthritis. The public must be educated so that they will recognize the early symptoms.

The general practitioner knows too little about arthritis and little about therapy.

The orthopedic surgeon knows little about the medicines for arthritis, but knows therapy.

The rheumatologist knows the medicines, but no orthopedics.

My experience has been one of running circles. We definitely need a general practitioner who knows the medicines and some therapy in order to bridge this gap.

If we can put a man on the moon, we can find the cause of arthritis. This is a statement I hear often.



I think Federal funds should be used for education, research, and better physical therapy facilities.

HELEN HAZEL  
Little Rock, Arkansas

November 12, 1975

Little did I realize some four years ago, after an automobile accident, that the little, constant, persistent, nagging pains would lead to my physical status today. No longer do I accept this pronounced degenerative disc disease as a minor complaint.

After thirty happy years as a public school teacher, I found during the past year that I could no longer endure these once simple movements of sitting, standing, and bending as I once had in the classroom. Needless to say, having begun my profession at the age of 19, I was not ready to give up a career that had been my life enjoyment.

The trauma came on June 6, 1975, when I realized that I could no longer function in my job employment because of the pain from which I am rarely free, limited body mechanics, and my frequent periods of being totally incapacitated.

My home treatments involve drugs, heat, therapy, and exercise. Injections have been used, thus far all bringing only short periods of remission from my daily discomfort.

Since the National Arthritis Commission's hearing will be held in our city November 12, 1975, I sincerely hope more funds will be allocated to support the clinical research centers that possibly will find a method to improve the treatment of this significant, painful problem so very prevalent among the people in our country today.

KATHLEEN HERZOG  
Little Rock, Arkansas

Our family's nightmare began in July of 1972 with the birth of my sister-in-law's first child. Although she had a difficult pregnancy and a breach delivery, we did not realize that this was only the beginning of what was to become a three-year ordeal.

Several days after the delivery, Charlotte, my sister-in-law, began experiencing severe joint pain and inflammation. In two days' time, her spine was so affected that she was bedridden, unable to move. The joints in her hands and feet were also inflamed.

After receiving little relief from the prescribed aspirin and little information from her family physician on why this was happening to her, Charlotte saw an immunologist. After a battery of tests were completed,

Charlotte's diagnosis was confirmed. She had systemic lupus erythematosus.

During the two and one-half years that followed, Charlotte experienced nearly all facets of this strange and little understood disease.

We learned as much as possible about this disease called lupus - that it frequently affects women during childbearing years, that it is classified as a collagen disease, and arthritis research monies go to lupus research, and that at this time there is no cure.

Because it is a systemic disease, lupus often affects many organ systems of the body.

Charlotte's case began with arthritis-like symptoms. She later developed kidney involvement and was on dialysis the last months of her life. The central nervous system, affected by the disease, produced convulsions, hallucinations, and psychosis.

Charlotte died in March of this year, less than two months before her 30th birthday. In lieu of flowers, our family requested that donations be made to the Arthritis Foundation.

I would like to see more public education materials developed by the Foundation on SLE and more dollars invested in SLE research. An accounting of what percentage of each dollar donated to the Foundation goes to lupus research would be informative and would give hope. Lupus outpatient clinics similar to one that is conducted at the University of Arkansas Center for Medical Sciences is a way of helping the patient and family cope with the disease. I think these clinics should be more prevalent and better publicized. I also feel there is a dire need for a more intensive effort toward physician education on SLE.

PAT HOOD  
Brookhaven, Mississippi

October 30, 1975

I am happy to give my statement of appreciation for what the Mississippi Chapter of the Arthritis Foundation has done for me.

Almost two years ago, I was a healthy, active person of 62 years. My hands became numb and began to swell and were very sore. I went to my local doctor, and he referred me to a doctor of internal medicine. This doctor diagnosed my ailment as a mild case of rheumatoid arthritis and recommended taking light aspirin each day.

I continued to work with much discomfort and discouragement. My knees became stiff and my ankles swollen.

A little more than a year ago, I learned about the arthritis clinic at my local county health department and was given an appointment.

Since that time, my condition has improved greatly, both physically and mentally. I have obtained reliable treatment and instructions on what to expect and how to take care of myself.

I never realized until I became an arthritis victim that so many people in my community suffered so severely from this ailment. I never expect to be completely rid of what arthritis has done to my body, but I'm really grateful for the aid the Mississippi Arthritis Foundation has given me.

BERNICE HUDSON  
Little Rock, Arkansas

October 22, 1975

The heated pool has tremendous effect on the aches and pains of arthritis.

So, I wish we had a pool to be available every day with therapist on duty at all times. The arthritis pool should have a whirlpool with it.

With a pool like this, a person should be able not to have the crippling effects for a continued stretching of muscles is helpful.

ELIZABETH E. JAMES  
Jonesboro, Arkansas

October 30, 1975

I hope that you will receive my letter before your deadline of the 31st.

I have had rheumatoid arthritis since the age of 12. I am now 28 years old.

I graduated from Manila High School at Manila, Arkansas. I now am attending Arkansas State University in Jonesboro, Arkansas. I am a senior there.

I am married, but we have no children yet, as my husband and I would like to further our educations before starting our family. My husband's name is Eddie J. James.

I have had many, many problems learning how to live with my arthritis. However, I feel that I know how to live with it and the pain involved.

Naturally, I have complaints about a few doctors and how they have handled my case. I also have many complaints in addition to praise for the Arthritis Foundation in this State.

If you could use my testimony or some more written statements, I would be glad to help you. I will still be in school during this time, and, of course, I will need to be there.



Thank you for all you are doing to help my disease and those of many other arthritics.

EURA KINNAMOUTH

October 21, 1975

I suffer from arthritis and have for approximately 20 years. It affects my feet, hips, and hands, and at one time or another almost all the other parts of my body. My left leg is two or three inches shorter than my right leg, and I walk with one crutch and one cane.

I've been to dozens of doctors over the years and have encountered much expense from this disease. Most of the doctors say they don't know very much about arthritis, and I should try to live with the pain and take my medicine.

I am now past the age to benefit from the joint replacements which are now so common. I have difficulty taking many of the medicines also because of my susceptibility to side effects. I do benefit from the hot water pool therapy the Arkansas Chapter of the Arthritis Foundation sponsors two times a week at a local hospital.

The following items should be covered if you are thinking of a total program to fight arthritis:

- (1) More specialists: There are very few specialists around, and they are so expensive most people can't go to them.
- (2) Research: I feel that some forms of arthritis can be cured, and it is just a matter of time and effort we put into it.
- (3) Facilities: Each state should have some specialized treatment facility for people who are afflicted with arthritis. These should include pool facilities and treatment areas staffed by doctors and physical therapists.
- (4) Local training of doctors: Most of our local physicians are not well schooled in the diagnosis and initial treatment of arthritis. Since they are the primary health care providers, they should be retrained. They don't like to treat arthritis because they feel so helpless.
- (5) Physical therapists and nurses should be better schooled on the importance of a continuous home program. It does very little good to treat the patient in the hospital and send him or her home without a good home instruction in heat, rest, exercise, etc.

Good luck with your study.

BILLIE KIRKPATRICK, R.N.  
Magnolia, Arkansas

October 24, 1975

As an occupational health nurse, I see many arthritic patients. They all have a common complaint: pain. Their pain and limitations often result in loss of work days, and some eventually are unable to work and must quit their job. Of course, their disease affects their home life, family relationship, and social life.

They all have a common need: adequate medical treatment and direction. These people need someone who cares about their arthritis and their treatment; they need hope and encouragement.

Most general practitioners do not have the time nor specialized education for arthritic patients, and these patients become disenchanted with their treatment, progress, prognosis, and themselves.

Arkansas needs professional help, made available to those who can or cannot pay. Not many arthritic patients can afford to go to Ardmore, Oklahoma, for treatment, for example. Better physical therapy facilities are also needed. One physical therapist in a county cannot serve the entire populous.

Additional funding is a must for research and a hopeful cure for the still unknown cause of arthritis. At the same time, professional knowledge should be shared and made available to all arthritic patients.

Thankfully, my own arthritis is in remission, but I know, as others do, that this status could change abruptly. Then what?

BETTY CRANSTON MONTGOMERY, R.N.  
McGehee, Arkansas

October 28, 1975

My mother, Mrs. Elizabeth Cranston, fell and broke her wrist in 1965. She suffered much pain. Shortly after her cast was removed, she began to have severe pains all over her body. She was soon diagnosed as rheumatoid arthritis. She was put on cortisone and other medicines to try to keep her out of bed. She became very helpless in just a short time.

I asked her doctor to refer her to an arthritis clinic or specialist, but she became very ill with phlebitis and wasn't able to go anywhere but the local hospital. She became anemic and had kidney infections. Finally, we did get her to the Little Rock Memorial Hospital for physical therapy and baths. She stated repeatedly she was so tired. I wish we could have taken her to an arthritis clinic at the beginning of her illness and been counseled about how to cope and what to expect, etc. She was finally receiving so many kinds of medicine the doctors thought this might have caused the prevention of red blood cells to mature. She had to have transfusions every few months. We finally used up most of her Medicare hospitalization.

We heard of a treatment in Mexico, and the local doctors stated they had nothing else to offer, so we tried it. She was relieved of pain for a

few days, but one of the side effects of the drugs she received there was to make the anemia worse.

She finally became totally helpless. She could not, or would not, feed herself. Because of the hospitalization problem we had to admit her to a nursing home. There were no facilities for physical therapy at all. She was lifted into a tub of water one or two times a day. The last six months she became more crippled and had arthritic knots all over her scalp. The local doctors kept saying she could live for years like this and didn't want to give her much for pain. She suffered so much. She passed away September 27, 1974.

Please do what you can for these patients. My mother had five years of suffering. Some people have this disease a whole lifetime. Please do what you can towards research to find the cause and a cure. Please see that terminal patients get something for pain, just as terminal cancer patients do. Please establish a hospital or center for arthritis patients where they can receive care for years, if necessary, without worry of running out of hospitalization (no Medicare limit on days), and let the patient pay according to income. A center with specialists who know how to treat the disease and can educate the public and medical personnel in outlying areas about the disease and the danger of overmedicating with cortisone and other medicines.

THELMA A. OGLESBY  
Hope, Arkansas

October 27, 1975

I received the Arthritis Newsletter and read of the request for statements from arthritic patients from the State of Arkansas.

I have had osteoarthritis arthritis in my hands since 1950, when it started in my index fingers. I am a free-lance writer, and this has hindered my typing quite a bit. I do continue with my work, in my home office. Am writing at present for arts and crafts magazines, doing photo journalism.

I also have a touch of arthritis in my ankles and knees, but it has not seriously affected my family life. I have a husband and a son, who married a lovely nurse; they have three children: boys, 18 and 16; a girl, 12.

Housework can be a problem; peeling potatoes, gripping the paring knife was painful so now I bake them or boil them with the skins on, and the ready-peeled frozen in the supermarket are wonderful to use.

No one knows until they have had a crippling disease what it means to live with some form of pain every day and to smile when you feel like crying. For you soon learn that crying will not help, but smiling will, and trying to be cheerful and counting your blessings every day. I try not to think about my disabilities or talk about them. It is better to look around and try to find someone worse off than yourself that you can help along the way. For everyone is disabled in some way. I do church and community work and work one day a week at our local hospital with the



hospital auxiliary. Seeing people who cannot get out of bed makes me thankful I can walk down the hall, carry flowers and letters to them, and work in the gift shop.

I also do oil painting and sell some. Collecting dolls is also a fun hobby.

I would like to see more funding for research into the cause and cure of the disease, and the need for better physical therapy facilities, and perhaps some day we can stop this crippling destroyer called arthritis.

VIRGINIA J. OWENS

October 20, 1975

I am an arthritis patient who is deeply concerned over the many effects the disease has on me and many others who have it. For about three years before I actually knew I had arthritis, I suffered through many difficult times.

Trying to work in public and at home and going to different doctors who told me it was muscle spasms and pinched nerves. The doctors I first went to considered my age, which was 27 at the time, and never ran any kind of test. They gave me medications, and I would try to continue on with my regular schedule until my condition got worse. The doctors still treated me as above, but suggested I try to lighten my work. I asked for, and got, easier work at the place I was employed and tried to rest more at home. This helped for a while, until the day came I couldn't even do this. I decided something had to be done. I contacted another doctor. He was very thorough when he checked me. I filled him in on past treatment and results. He ran tests that showed what my trouble actually was, rheumatoid arthritis. At this time I had severe pain and swelling in the hands and at the back of my neck. I could not turn my head nor had very much use of my hands. He started me on a different type of medication, complete rest during the time of severe pain and swelling, and regular visits to see him. I had to quit my job due to my condition. This put a financial burden on my family, especially with all the past medical bills.

Things even had to go undone at home due to my condition, except what my family and friends helped with. At this time, trying to adjust to my condition, having to quit my job, and having to rely on others for help began to affect me emotionally. I would have a good day and try to do things and then have a setback due to not knowing how to cope with arthritis. The doctor I was going to at this time was very concerned. He saw I needed help in more ways than one. This is when he decided I should go to a meeting that the Mississippi Chapter of the Arthritis Foundation was having. I went to the meetings. The first one, a doctor spoke to a group of people of all ages. I was hesitant about going, but I knew I needed answers from somewhere. I was very mixed up. The doctor explained many things about arthritis and its effects, treatment, and drugs. This helped me to want to fight and to accept what I had. The next night, another doctor and a druggist spoke. This was even more helpful to me. I actually looked forward to the next night. A physical therapist spoke and showed many things and ways a person with arthritis could be helped.

Another night, a dietitian talked about foods and how to keep the diet well balanced. The last meeting, a psychiatrist talked to the group and tried to explain a way to help yourself emotionally. Through the help of all these, I had more understanding about arthritis and what it actually was and its effects. The Arthritis Chapter, whose meetings I went to, was 90 miles from my home. Also, the doctor I was going to. The distance plus the financial burden was hard for me, so the doctor advised me to contact a local chapter in my county.

I called the state chapter and found I could attend the clinics in Jackson, only about 36 miles from home. They offered their help in setting up an appointment with a doctor I could use closer to home. Helped with my medical treatments and bills. They helped to get things I needed to help correct some of the physical damage, such as splints, a paraffin bath, special shoes, and other things that help to fight the battle of arthritis. If it had not been for the Mississippi Chapter of the Arthritis Foundation and their help, I would have had to do without these things. This doctor helped me to get disability Social Security, which has helped to catch up on past bills and help with daily living now since I am unable to work. The arthritis has affected other parts of my body since then, but with regular visits and treatment from the doctors and therapists and home therapy, I am learning to cope with arthritis better.

I have had surgery on one of my hands, and in the future there will be more surgery to help correct some of the damage caused from arthritis.

Rehabilitation is also helping me. In the future, I hope there will be even more done for this disease. The main thing to learn is how to care for yourself and just how much you know you can actually do without causing more harm than good.

I feel like there should be more research done on this disease. It affects people of all ages and in so many different ways. I believe there should be more understanding and concern from doctors like the ones I first went to. There should be more knowledge of the disease explained to the patient about the effects of the disease and how to cope with it. If it had not been for the one doctor out of many I went to that sent me to the Arthritis Foundation for the meetings, I would be in a very confused state and probably wouldn't have fought the disease daily.

I also believe the Government should see that each county provides services. Not just for financial aid, but to help the person learn more about how to help himself.

Finally, I certainly would like for anyone to come up with a cure. No one wants to live a life filled with such pain and difficulty and emotional turmoil.



WALTER RINGO  
Little Rock, Arkansas

October 22, 1975

My name is Walter Ringo, and I have been fighting arthritis (rheumatoid) for thirty-five years. At first I listened to all the remedies my well-meaning friends suggested and tried them all with no result. Any part of my body giving pain I tried to use as little as possible and give it a chance to heal, which was the worst thing I could have done. Finally, I went to a medical doctor who felt he had a new cure. He injected typhoid serum in my veins every Saturday for three months, and I would go home and to bed with chills and fever. But at the end of three months the doctor admitted he had not done a bit of good, but I owed him \$300.00.

My right arm became so stiff I could not comb my hair. And I went to another doctor who put my arm in a cast for several weeks with my arm stuck up in the air. Today, I cannot reach further than the top of my head with that arm. I moved to California, and a doctor there gave me gold shots and vitamins to build up my system. The gold shots helped, but I gave them up because of the cost. My feet felt like they were full of thorns or stone bruises, and I tried orthopedic shoes, tennis shoes, or anything that would help, and finally had both feet operated on and the calcium removed. This was ten years ago, and they have not bothered me since.

My back bothered me from no cause whatever, and my company sent me to several specialist who decided the trouble was rheumatoid arthritis. One of the specialist put me on Indocin and aspirin, and Standard Oil paid me sick leave for five years and then retired me on a pension.

I moved to Little Rock to be with my mother and spent thirty days in Levi Hospital with no result. Levi Hospital suggested Dr. Ross, and I have been under his care for nine years. Dr. Ross recommended pool therapy, and I have had more results there than any amount of pills could do. The pool relaxes me, and I can use my muscles without pain. I leave the pool without a pain in my body and always starved to death. Alas, the pain is back in about a day's time, but I have had that much relief and a good rest.

I think the Arthritis Foundation needs their own pool, and it should be open at least five days a week. I think we need the whirlpools and massage along with the pool and a staff of qualified workers.

I think we need a TV program at least once a week to educate the public on arthritis and where to go for help. I think we need more trained doctors and workers who can help you before you are crippled.

I think we need a revised medical program that will take care of the people, be it medicine or doctors' care. Medicine alone cost mother and I over sixty dollars a month and Medicare and Blue Cross do not entirely take care of medical bills.



November 12, 1975

RELDA SMITH

October 27, 1975

My name is Relda Smith. I am 37 years old, and I am the mother of two children, ages 17 and 12. I have had arthritis ten years.

Before receiving aid from the Mississippi Chapter, Arthritis Foundation, my illness was using up a large portion of our income (approximately \$100 each month). Without the foundation I would have been unable to take the gold treatment. I am sure this treatment has helped me. I had taken this treatment once before, but I was unable to continue it because of its high cost. The Arthritis Foundation has helped take the severe strain off our family budget.

I no longer have to pay for some of my medicine, and the Foundation has paid for my gold treatment for two years. I am truly thankful for the fine facilities in Lincoln County, Mississippi, and I hope that the clinic will continue.

I believe the Arthritis Foundation will find a cure, if not for me, maybe someone in the next generation. I think everything should be done to assure there will be monies for the research and patient care to continue.

MRS. NORMAN WILLIAMS

November 12, 1975

This is my testimony concerning my condition. Sorry I didn't get the notice before November 8, 1975.

I have been bothered with this since about the spring of 1972, going from one doctor to another, but I didn't know what the trouble was until November 30, 1973. I was at the hospital in Little Rock (Medical Center). Dr. Wilson and Dr. John Watson waited on me. They told me I had rheumatoid arthritis, so he called the Foundation for some special treatment for me. They sent a representative to my home January 22, 1974, and he recommended paraffin wax, which I used regularly for a long while, but not as often now. At the time he came to see me, I was almost past feeding myself. He has been to my home three times. I have made several trips to the medical center in Little Rock. Dr. Lipsmeyer is my special doctor there. I have improved a lot since I was there on October 21, 1975.

I am unable to do work. My family understands pretty well. My doctor told me about the hot bath. Since I can take them, they are a lot of help to me, and I can dress myself and prepare my breakfast some mornings during the last month.

With your help and the mercy of God, I'm not in a wheelchair, thank the Lord. I hope I have said what you wanted me to say and what was necessary.

WILLIAM C. FINCH  
Little Rock, Arkansas

November 12, 1975

The first encounter with a person stricken by arthritis that I can remember was about thirty years ago. The woman, a friend of my parents, was a victim of rheumatoid arthritis. Though only in her early forties, she was bedfast and totally dependent on other people for even such simple things as holding a glass of water or changing her position on the bed. When my parents and others would talk of her, inevitably the words "cheerful, inspiring, and courageous" would be properly applied in describing the personality traits of this remarkable woman.

Her condition and situation created a question in my mind that I, as a teenager, could not resolve. How much worse could death be than to live like this? I am sure that question had much to do with the reason for my deep involvement in the fight against arthritis.

Certainly, the most critical area for funding in the arthritis program is research. This must be a well-coordinated effort to make maximum use of the available funds. This cooperation should include research activities of the Arthritis Foundation and its local chapters, national arthritis hospitals, and those projects instituted by other commissions, such as cancer. It is my understanding that some of the drugs used in the control of cancer also have application in controlling some forms of arthritis. Cooperation between those involved in both research areas would be most desirable. The extremely high cost of research dictates the necessity for avoiding a duplication of efforts.

By the same token, the high cost of arthritis to our country in production losses and quackery racketeering dictates the necessity for a research program of sufficient magnitude to find a cure and a prevention for the disease.

A very necessary part of any effort in the research area will be an intensive recruitment of and training program for medical and health specialists in the fields of rheumatology and immunology. It would seem that this could be most efficiently and expeditiously done, in most cases, at existing arthritis centers.

The victims of the disease should also receive top consideration in the programs to be funded. A comprehensive patient service concept should be developed, including home evaluation of patient and environment, hydrotherapy pool treatments, area clinics staffed by registered physical therapists and physicians participating on a consultation basis. This program could probably best be implemented by a local Arthritis Foundation chapter or some other nonprofit organization serving arthritis.

I am deeply appreciative of the efforts of the National Arthritis Commission, and I sincerely feel that with proper guidance and application we are at long last on the move toward the goal of every prudent physician: the elimination of pain.

BILL KELTNER  
Little Rock, Arkansas

November 12, 1975

I speak not as a physician, but as a concerned citizen in our community. I know statistically the number of people affected by arthritis, and I am deeply aware of the efforts being made by the Arkansas Arthritis Foundation. I have been particularly concerned with the lack of Federal support for research activities in the field of arthritis. I feel that this is the real key to the arthritis problem in our country, and that a substantial amount of research money should be allocated in this field.

With roughly one out of every 10 or 11 people being affected by arthritis, I would think that this offers a broad enough base to make expenditures in this field acceptable to the Federal Government. I know that as prevention techniques can be developed and cures developed, it certainly will return many times the investment put into the research effort.

I know several people who have serious cases of rheumatoid arthritis, and I know how much they suffer from this disease. More than that, it restricts them from many activities with their children and their friends. I have had a mild form of arthritis myself and recognize that my restrictions are magnified manyfold for those with serious cases. I don't know what percentage of those in Congress have had a direct contact with arthritis, but I am sure that many have. I would hope that their concern in this area will show a willingness to spend some of my tax money to combat the arthritis problems. I know that many dollars are being spent for activities far less important to the general public, certainly to me.

I can't speak for the entire country, but I do know that Arkansas is fortunate to have a group like the Arkansas Chapter of the Arthritis Foundation already in existence and doing their best to educate, care for, and devote some money to research in the field of arthritis. I know that the Arkansas organization is well run, has accomplished a tremendous amount of outreach on a very limited budget.

I have been involved in many charitable organizations and currently serve on the board of directors of three United Way agencies in our community, and I can say without qualification that the Arthritis Foundation is as well run and effective as any organization I have ever been associated with. I think because of this the citizens of Arkansas have a good taste in their mouth for the effort that is currently being made with arthritis and would certainly welcome an expanded effort.



A. T. MASI, M.D., DR. P.H.  
Memphis, Tennessee

November 5, 1975

Due to my long-standing commitment to introduce a visiting scientist who will deliver one of this year's distinguished lectures in rheumatology at the University of Tennessee Center for the Health Sciences in Memphis, November 12, I will be unable to attend the public hearings of the National Arthritis Act Commission in Little Rock. I appreciate the opportunity to submit this letter expressing my views for the consideration of the Commission.

My responsibilities at present include being Director, Division of Connective Tissue Diseases, at the University of Tennessee, director of an NIAMDD training grant in arthritis, principal investigator of a multidisciplinary clinical research grant in the study of early arthritis, chairman of several committees of ARA dealing with therapeutic and diagnostic criteria of rheumatic diseases, and Cochairman of the Epidemiology Work Group of this Commission. The comments to follow are strictly personal, based upon my own clinical experience and research in internal medicine, epidemiology, and rheumatology, and do not necessarily reflect any position that I may hold.

Public and legislative sentiment is growing to alleviate the impact of the arthritis problem and that of other chronic diseases. Progress in treatment or prevention of most forms of arthritis has not been as rapid as the great strides made in advancing knowledge of various laboratory and experimental factors related to these diseases. Some notable examples of progress include joint replacement and use of xanthine oxidase inhibitor in the treatment of some forms of gout, and illustrate the importance of patient-related research.

In spite of logarithmic increase of research funding, professional efforts, and publications during the past several decades, the alleviation of the problems encountered in rheumatoid arthritis, diffuse connective tissue diseases, and other forms of chronic arthritis, is only moderately advanced at present, with considerable gains still to be made. The question I respectfully raise for the Commission is whether or not a greater investment in similar research directions will pay off with the desired results in the near or not too distant future. I would like to suggest that perhaps our present priorities and directions in research are not either sufficient or optimal.

Priority and emphasis in research at present is given to detailed in vitro studies of molecular reactions under highly controlled conditions as opposed to emphasis on studies of pathophysiologic processes in arthritis patients versus controls. The focus increasingly is at the level of cellular or molecular reactions, or in search for virus, than on the host with arthritis. It is true that a complete understanding of disease will require knowledge at the molecular level, but it is equally true that an understanding requires knowledge of the abnormal host processes in vivo and in relation to the environment, social, occupational, and other global interactions. It is not known at present what abnormalities might be most predisposing to the arthritis diseases or whether viruses may play a role.

An expanded research scope might provide better clues as to directions of future investigations and therapy.

At present, the question seems to be one of defining the total spectrum of research needed and to define priorities or achieve an optimal balance in the face of limited resources. Obviously, total investment in either laboratory experimental approaches or patient-applied research would be unwise. A balanced research investment is needed which would give maximal benefits in developing disease concepts, revealing new research opportunities, and understanding arthritis. Without compromising the momentum and investment of current directions in laboratory experimental research, I would submit that insufficient in vivo research is being conducted in physiologic, microvascular, metabolic, endocrine, biomechanical, and neurogenic systems of patients with various chronic progressive forms of arthritis as well as research on the host per se, including epidemiology, genetics, psychology, economics, and a gamut of clinical-therapy aspects. More data are needed on global phenomena of disease as they relate and interrelate to various host systems, as opposed to individual cellular or in vitro phenomena, if we are to understand the total process of the arthritis diseases. Putting a greater focus on the patient as a whole and also on his interaction in the environment may be as important, if not more important, to an understanding of arthritis disease (and health) as attention paid thus far to present laboratory experimental approaches.

By virtue of the overwhelming information expansion and specialized technology, an insidious process has evolved of emphasizing the more restricted, controllable phenomena at the sacrifice of more general clinical relationships. The need is most pressing to develop host- and disease-related studies if a proper relevance and coordination is to be maintained between experimental and applied patient research. Suggestions have been made to create special research career development awards for clinical scholars or patient investigators of this type who might be induced to follow such an arduous career which now lacks sophisticated technology and promises slow research results as opposed to many in vitro or animal model investigations. Again, no one pursuit is a priori superior to the other, but each is necessary for a complete understanding, proper balance of scientific efforts, and for productive interaction and progress.

Assuming that an expanded scope of research is justified and should be pursued in the future, then one must consider what resources are needed, including professional, organizational, facilities, funding, and other essentials. A considerable investment has been made over many years in the implementation of experimental laboratory approaches, and, similarly, development will be needed in these other expanded areas of research if it is to achieve the desired levels of scientific productivity. At present, a minority of arthritis investigators have prepared themselves or are actively engaged in areas of host-related research. This is especially true of trainees and junior investigators who have not yet acquired their own patient series or disease interests. The minority of centers have well-developed patient follow-up procedures, with detailed data collected on a protocol basis which is readily accessible to trainees for pursuit of relevant clinical questions. Also, resources are limited for clinical



research center type studies or prospective clinical observations or trials. Unless such patient and organizational resources are developed and made available, then one cannot expect these areas of research to grow and complement effectively the laboratory experimental efforts.

Ideally, some competition for the best minds and available resources should exist between different areas of research rather than certain established approaches preempting scientific investment because of technical or logistical conveniences. At present, most arthritis training centers can offer junior investigators one or more immediate research opportunities in the laboratory, but relatively few can offer the necessary resources to effectively pursue many types of patient-oriented studies; e.g., natural history of disease, therapeutic trials, or controlled studies in research clinics or inpatient facilities. The latter usually require a certain degree of logistical and organizational development which, when lacking, tend to frustrate pursuit of relevant clinical questions.

Inordinate time now transpires between the acquisition of a disease concept or the discovery of a particular factor and the testing in patients of its relevance to disease or therapy. Improved development of patient-oriented research resources will shorten the gap.

If greater scientific interaction is to be expected in the future, attention must be given to the development of multidisciplinary integrated research centers. Obviously, centers cannot be expected to engage in, or have competence in, all areas of research, as well as take responsibility for all levels of teaching and service delivery. Certainly, research and teaching should be highly integrated in the setting of exemplary patient care. No suggestion is offered regarding the optimal organization or balance of efforts in each major responsibility area; that is, integrated research, teaching, and patient care. Certainly, the prospect of comprehensive clinical centers might contribute to the development of improved organization whether such centers develop as physical structures or integrated, but distinct, cooperating units.

Our arthritis program at the University of Tennessee has strived to develop in a comprehensive laboratory and clinical research fashion, with training opportunities available in each area and with integrated patient care responsibilities. The organizational and administrative investment has been heavy, with insufficient professional resources available for optimal or desirable productivity. Nevertheless, the interdisciplinary, integrated approach has been effective in training and is academically rewarding. Significantly improved results in research and service efforts can be expected from a greater professional and funding investment in this approach. New concepts are developing and being tested in areas of microvascular involvement and endocrine-metabolic alterations in the rheumatic diseases which have potential direct therapeutic application, in addition to active research in more conventional areas of immunology, collagen biochemistry, and clinical epidemiology.

In summary, from a generalist viewpoint, and as one who has been engaged in research areas closely related to host factors and interactions, it seems that numerous areas of potentially rewarding



research in arthritis have been overlooked or inadequately developed, whereas other areas of in vitro laboratory investigation have greatly expanded, if not preempted, the field. Without threatening established discipline productivity, additional research development seems urgently needed in patient-oriented areas as described. A far greater understanding of complex host systems interactions will be needed to understand the host predisposition to arthritis diseases, their pathogenesis, natural history, and best approaches to treatment. To achieve desired goals, an immediate investment in developing professionals trained to conduct research in patient-related areas is needed as well as support for functional or structural organizations to implement such research development.

Criticism has been expressed from certain public and legislative sectors that the medical profession is not serving the public needs as well as it might be able to do. Greater investment in patient-oriented research can be expected to satisfy such demands. Furthermore, short-term direct patient care benefits can be expected from such additional patient-related research investment. It must be emphasized that this petition is for support in addition to existing research funding patterns, and that further integration should be developed between experimental laboratory studies and expanded patient-oriented research programs.

S. WILLIAM ROSS, M.D.  
North Little Rock, Arkansas

I support the general purpose and program as outlined in the National Arthritis Act.

The most urgent unmet needs are:

- (1) Better patient and physician knowledge of current facts and fiction about arthritis.
- (2) Continued research programs for more definitive answers to old and new questions about arthritis.
- (3) Acquisition of curative forms of treatment.
- (4) Public education for the arthritic to better demand better answers.

I would use additional funds to support basic and clinical research at university medical centers and supporting institutions.

JOHN V. SATTERFIELD, M.D.  
Little Rock, Arkansas

November 10, 1975

At the request of my brother, Mr. W. W. Satterfield, who is the past President of the Arkansas Chapter of the Arthritis Foundation, I am submitting the following statement as testimony to the National Commission on Arthritis and Related Musculoskeletal Diseases.

My family has had personal experience with rheumatoid arthritis. My father developed it late in life. Although it greatly interfered with his comfort and activity, it did not have a material effect on him economically since he had a top-level executive position. My daughter developed rheumatoid arthritis when she was eight years old. The disease has had a disastrous effect on her emotional and physical maturity.

I offer this testimony, not as an expert in the arthritic diseases, but as a surgeon and as the son and father of persons that have had the disease. It is my belief that more people with rheumatoid arthritis will be helped quicker by the discovery of the etiology of the disease. I therefore urge that as much resource as possible, if not 100 percent of it, be expended toward finding the cause of rheumatoid arthritis. I support this contention by pointing out the fact that many grave diseases are now either eliminated (example: poliomyelitis, malaria, smallpox, yellow fever), or are curable (example: tuberculosis, syphilis, bubonic plague), or are controllable (example: pernicious anemia, diabetes mellitus). These successes have come only through an understanding of the disease.

Gentlemen, I urge that as much resource as possible be expended on an effort to discover the etiology of rheumatoid arthritis.

ROBERT K. SELLS

My name is Robert K. Sells. Currently, it is my pleasure to serve as Chairman of the Board of the Arkansas Chapter, Arthritis Foundation. Prior to that I have been President, Vice President, Chairman of the Budget Committee, plus many other short- and long-term jobs.

My involvement with the Arthritis Foundation began about twelve years ago when my wife was given a diagnosis of rheumatoid arthritis by a general practitioner in Little Rock. It turned out that this was a completely incorrect diagnosis. A friend at church, who was one of only two rheumatologists in Arkansas at the time, explained that this problem of professional education regarding the rheumatic diseases was one of many problems the Arthritis Foundation was trying to correct.

Although a layman, this has been one of my main interests in working with the Foundation since that time, and the record in Arkansas has certainly improved in recent years, primarily due to the efforts of the Medical and Scientific Committee. I would refer you to the testimony submitted by Dr. Louis Sanders and Dr. Eleanor Lipsmeyer. Dr. Lipsmeyer now holds the Chair of Rheumatology at the University of Arkansas Medical Center. This chair was nonexistent at the time of my wife's problem, but

is now funded partially by the support of the Arkansas Chapter, Arthritis Foundation.

The above is strictly background information which leads me to the real reason for my submission of testimony in these hearings. My purpose is to hope and pray that your Commission and Congress will be concerned about fiscal and human priorities.

Because of my involvement with the Foundation, almost daily I have been in contact with people whose lives have been disrupted emotionally, economically, and physically due to the chronic pain brought on by arthritis. I have held a five-year-old girl in my arms before television cameras while the child gritted her teeth in misery because of the pain I was causing. I have had a mother come up to me following a speech and cry as she asked that we find help in a hurry for her husband and her daughter. I have seen a friend suffer through surgery and medical treatment only to know that it was all in vain. I have seen a fellow employee at the telephone company walk to a closet after a difficult installation job in order that he could cry without being seen by his fellow workers.

Worse, I have seen these and many others whose eyes asked for more, sooner. And yet I have known that with the present level of money being spent on research they would all be dead first.

These experiences have become even more difficult to accept emotionally or intellectually when I have also seen tax dollars spent on obviously less important research activities at most of the colleges and universities in the United States.

Research on alligators, bird migrations, Dutch elm disease, and literally thousands of other subjects are funded yearly by Congress. I would not claim that many, or maybe even all, of these tax dollars are not spent wisely. Certainly, the fact that much of this money keeps some teachers on campuses is laudatory.

But, I go back to my original thesis: Should we not give more consideration to real fiscal and human needs in the allocation of Federal tax money? If so, should we not look more closely at the economic gains to be achieved by finding a cure for the nation's number one crippler? Aren't the literally thousands of working men and women each year who are forced because of pain and crippling to go home and sit worth more economically to America than almost any of these other research projects funded annually by Congress?

And it seems almost ridiculous to compare the human needs of the nation's arthritics who cry out daily for help with existing federally funded projects that only give intellectual stimulation to a few Ph.D.'s on college campuses or private research facilities.

I honestly do not know how much money is being spent to promote the careers of entomologists; biochemists; nuclear physicists; Greek, Latin, or Assyrian language purists; paleontologists; lepidopterologists, et cetera, ad nauseam.



I don't want to know.

But I do know that people are suffering in America today, and not one cent is being spent on basic arthritis research by the government I proudly call mine.

I beg of you that Congress be made aware of priorities. And help my friend the little girl, her mother, my neighbor, my coworker, and the other 10 million Americans who are in pain daily and have nothing to anticipate except more pain, worse pain, and death.

HELEN TAYLOR  
Little Rock, Arkansas

October 29, 1975

I am sincerely and deeply interested in a national plan to fight arthritis. My primary and main concern is a more progressive program in Arkansas; for this to be possible, money and more money is needed.

The pain and discomfort that arthritis can bring to a person is known by me. Although I was under the care of a doctor and medication, the pain was still constantly present. My condition is greatly improved, but I do not believe I would be in as good a physical condition as I am today if it were not for Dr. Michael Harris and his knowledge to treat me. The Arkansas Arthritis Foundation has been most helpful. The two have worked together as a great team.

I would like to see more money allotted for research. We must not stand still. My firm belief is that the American people are of the high intelligence level to find the cause and cure of arthritis. We also need to know how to keep it from striking a person so severely. Money is needed to educate more doctors and push forward in research. Therapists need to be trained and educated. We need more trained personnel in this field so they can work closely with the patient in their own home and surroundings. To educate and train, lots of money is needed.

Arthritis is such a crippling disease, I feel it needs to be brought under control.

Since I know and have experienced what can be done by a doctor and therapist working as a team, this is the field I would like to see more money allotted to. We must push forward to fight arthritis and stop this crippling disease.

LOIS WALLACE

October 29, 1975

I am a woman of 41 years old. Two years ago, I found out that I had rheumatoid arthritis. I was recommended to a specialist in Jackson, Mississippi, a Dr. Thomas Wilson. Without Dr. Wilson's medical knowledge of arthritis, I would be unable to walk today.

Dr. Wilson said I needed to be hospitalized in order for him to give me immediate medical attention. I stayed in the hospital three weeks, unable to walk, bathe, or dress myself.

After hospitalization and home again, I did what the doctor advised me to do. He recommended hot baths, aspirins, and the gold salt shot. Also, he said I needed rest and plenty of good nourishment. This became my pattern of life.

Five months later, I could walk, bathe, and dress myself. My husband had taken care of me every minute of the day.

I have not fully recovered from rheumatoid arthritis. I have continued the treatments each day with the exception of cold baths, which I feel at this time is more beneficial than the hot ones. As the disease decreases, I have found cold baths are really better now at the stage that I have it.

Rheumatoid arthritis has damaged the joints slightly. I am physically weaker than before I got this crippling disease. I have a few mild pains every day in the joints and muscles. But due to a very good doctor, Dr. Thomas Wilson, I am not deformed yet. Dr. Wilson says, "God spared me."

Without the assistance of the Mississippi Chapter, Arthritis Foundation, and the Methodist Rehabilitation Center, which paid three more weeks of my stay in the hospital, we could have not been able to have the medical service that I needed. Even with the rehabilitation, this disease has been a great strain on my husband financially.

Because of my condition, my husband was unable to hold his regular job, so he set up a small welding shop by the house so he could check on me most of the day. He barely made a living because of our location out in the country, and the cost of my medicine didn't help finances any.

What I would like to have accomplished for arthritis is a research program in which each doctor in the country could learn at least a little about rheumatoid arthritis. Any doctor, whether specialized in this field or not, should be able to detect this crippling disease. Not treat the disease, but to be able to detect it immediately and recommend a specialist.

I had gone to several doctors before one of them could even guess at what was causing my pains.

I would like everyone to be able to be helped in time before this disease has gone too far with them.

The saddest part of this number one crippling disease is the fact that it spares no one at any age.

I think more people would be less crippled if they had consulted a doctor who knew right away that they had rheumatoid arthritis.

Finding a cure would be the answer, but funds are so limited that this is almost impossible. Should our country, our Government realize that this is our number one disease as acrippler and it should be abolished as quickly as possible.

I think America, the Federal Government, does find it in their hearts to help its people be good, strong, healthy Americans. With research programs, money for medical help, we could lick this problem for the people of America forever. It just takes capital. Each and every person needs to be concerned because this is one disease that could strike them at any one time in their lives.

I am truly thankful to all that has helped me live a more normal life after my rheumatoid arthritis condition.

I thank God, my doctor, the Arthritis Foundation, and all who have participated in my near recovery of this disease.

Please help us so we can help ourselves. There is more money needed to combat this disease, to find a cure once and for all.

Thank you.

E.K. CLARDY, M.D.  
Hot Springs National Park, Arkansas

October 28, 1975

I would like to have some input into the hearing on arthritis. I would like to identify myself. I am Medical Director of Leo. N. Levi Hospital in Hot Springs, which treats arthritis almost exclusively, and have been here for 24 years.

In reviewing the request for input into this, I notice that you wanted opinions on primary needs in this field.

I feel that there are plenty of research centers for arthritis now. Possibly better support of these research centers would be appropriate, but they certainly have the staff and know-how and plenty of the desire to do a credible job. I believe that more research centers, especially away from population centers, would be a waste of money and talent.

I feel that training for primary-care physicians to recognize the various arthritides and give basic treatment for these would be very helpful to patients. Obviously, this does not have to be carried out in a research center.

So far as patient care goes, I feel that the whole gamut of insurance coverage is available through Medicaid, private insurances, and Medicare.



The coverage seems to be adequate, but certainly pressure for expansion of coverage with Federal agencies would be a big help as trying to accomplish a great deal with a two- or three-week admission in a hospital or physical therapy treatment facility is difficult.

I feel that research on antiarthritic drugs far removed from research centers is not very appropriate. It takes way too long to get a new drug into the hands of a physician to treat arthritics even when a proven benefit overseas.

I notice the concern about arthritis in children (by various names). See the enclosed copy. I just don't believe that the volume of childhood arthritis is present in Arkansas as indicated by the statistics. We don't have that kind of case load, nor does anyone I know of.

I believe the basic need in this area is training registered physical therapists to give basic physical therapy and training to arthritic victims. I believe this is a very important need.

Lastly, on a practical basis, I feel that a good orthotist who is able to make proper braces and devices and especially shoe corrections is most important in the everyday care of arthritics. I get more good for my patients from the skilled assistance of my brace man than from any research that I am familiar with in the last 30 years.

I hope this information is of some value.

[Appendix submitted by Dr. Clardy]

STATISTICAL ANALYSIS OF ARTHRITIS AND  
RHEUMATIC DISEASES IN ARKANSAS

Pop. 1,926,146

The statistics contained in this report are based on the 1970 National Health Education Committee Fact Sheet. The Arkansas Chapter modified these statistics and developed a conversion factor which may be used to determine incidence and cost within any community having a known population.

These figures are accurate only in average communities. Areas which vary greatly from the national average in occupational groups or income level will show a corresponding divergence between environment and rheumatic disease incidence.

To use these conversion factors, multiply the community population by the conversion factor to arrive at the local statistics for information desired.

Example: Gout in Sebastian County (Pop. 79,900)

Conversion factor	X	Population	=	Est. No. of Gout Patients
.00240	X	79,900	=	192

General Incidence

	<u>Conversion factor</u>	<u>Total in Ark.</u>
A. Total Arthritis & Rheumatic Disease	.10300	198,393 <sup>D</sup>
B. Arthritis Only	.06200	119,421
C. Gout	.00240	4,623
D. Children Crippled by Arthritis	.0004	770
E. Juvenile Rheumatism Arthritis (Stills Disease)	.00121	2,331
F. Juvenile Arthritis and Rheumatism	.00025	482
G. Completely Disabled	.00175	3,371
H. Disabled Part of Time	.01001	19,281
I. New Cases Each Year	.00150	2,889

Economic and Work Factors

A. Restricted Activity (Man Days)	1.43	2,754,389
B. Bed Disabled (Man Days)	.33275	640,925
C. Work Loss (Man Days)	.15950	307,220
D. Forced to Change Jobs Because of Arthritis	.00171	3,294
E. Veterans Receiving Compensation with Arthritis Major Disability	.00161	3,101
F. Rendered Unemployable by Arthritis	.00213	4,103
G. Total Cost to Community (Wage & Salary Loss, Tax Loss, Private & Government Medical Care & Welfare Cost, Etc.)	\$ 16.90	\$ 32,551,867

Little Rock, Arkansas

November 12, 1975

FRED A. HUTCHESON, M.D.  
Texarkana, Arkansas

October 21, 1975

I wanted to express some views on arthritis in connection with the National Arthritis Commission hearing to be held at Little Rock, Arkansas, on November 12, 1975. I feel that there are several urgent, unmet needs as regards arthritis. There is a great need for further public education as regards this problem and the different types of arthritis. There is also a need for more available programs in training institutions, such as the University of Arkansas Medical Center, to interest and to train physicians in arthritis diagnosis and treatment. This could be in the form of fellowships, grants, scholarships, or something of this sort. These physicians would then, hopefully, be encouraged to go out into the communities and spread their knowledge to other physicians, and, of course, to the patients. Physical therapy is now offered in most areas of Arkansas by the Arkansas Arthritis Foundation, but I think this program could hopefully be expanded with the patients being seen more frequently and with more close supervision if more funds were available. Physical therapy is extremely important, and the physician often does not have time to work in this area as much as he needs to. In addition, more facilities for home visits, for closer supervision of medications, and to check on patients' progress in the physical therapy modalities would be helpful. Needless to say, research into the area of arthritis would be much aided by increased funding to the various educational institutions who are working on the etiologies, diagnosis, and treatment of the various types of arthritis, and I feel that channeling of funds into this area would be extremely beneficial.

It would be very useful if physicians as a whole could be made more interested in arthritis, better educated in the treatment of this group of disorders, and aided by properly trained paramedical personnel in the care of arthritis patients. National coordination of research efforts and treatment efforts would be useful to help diminish duplication of effort in all these various areas that I have mentioned. Education of not only the patient but also the family involved would be useful, of course.

DOROTHY NOTTINHAMPER  
Little Rock, Arkansas

October 30, 1975

I am writing to express my concern for the arthritis problem. I have had arthritis for the past four years, and have been retired since August 1973.

I feel that more should be done in the area of education and research. In-service programs at hospitals to educate professional and nonprofessional staff. Medical students should be required to do a tour of duty and training in this field whether or not they choose it as a specialty.

The first thing I encountered at the onset of the disease was the inability of the physician to determine my problem. It was after I had consulted five physicians that a diagnosis was made. I had rheumatoid



arthritis, but the seriousness of the disease was not stressed. I was discharged and instructed to take aspirin for pain and continue my usual activities. Eight months later I experienced an acute attack which completely disabled me. It was at this time I learned I had a more severe form of the disease involving the vascular system.

I believe early diagnosis and treatment is important. If this is accomplished and the disease controlled, there is less chance of serious involvement.

Teaching programs to help the patient learn about the disease.

Education and assistance for families, particularly parents of arthritic children. Counseling for patients who find the disease and its complications overwhelming.

More treatment facilities are needed over the state to assist people in rural areas. Transportation to and from treatment centers for wheelchair patients.

Increased funds for the purpose of research into the cause and cure of the disease.

ALLAN S. PIRNIQUE, M.D.  
El Dorado, Arkansas

October 22, 1975

I am a private practicing physician in southern Arkansas, in a community of 26,000. I have been in private practice a little over five years now. Arthritis and its related inflammatory musculoskeletal diseases are seen by me daily in my practice. I am submitting the following information for use by the National Commission on Arthritis and Related Musculoskeletal Diseases in regards to the recently established National Arthritis Act.

Needs in Professional Education: Professional education is certainly needed for the recent and rapid advancement in arthritis diagnosis and treatment. One problem is dissemination of the material. I believe that local visits by a physician trained in arthritis are quite helpful. A lot of local medical libraries are now equipped with audiovisual viewing equipment, and possibly dissemination of tapes for this would be helpful. The visits by the individual physician would probably be best attended if these were held at a short one- to two-hour session at noontime. Possibly a once-a-year, all-morning or all-day session would also be well accepted and worthwhile. Specific problems in education, that I have noticed, have been the distance between the orthopedic approach to arthritis and the internist's approach to arthritis. Perhaps something could be done to bring these two areas closer together. Another specific area in professional education is the rapidly developing diagnostic tests for being more specific in the type of arthritis or musculoskeletal problem that is going on. These are frequently seen in our medical journals, but the number and names of these tests are sometimes long and discouraging, and it would be helpful to know which tests have been adequately evaluated so they will be clinically applicable.

The Role of the Proposed Arthritis Centers in Supporting Programs of Education, Patient Care, and Research: I believe that the arthritis centers can work through the arthritis foundations that have been well established in the past. I believe that there would be a place for the occasional patient that requires specific care because of complicated long-term problems, and, for this reason, probably inpatient care at one of the centers for such patients would be worthwhile. It is my personal opinion that most of the monetary and manpower support for the arthritis centers should be directed towards basic research in hopes of finding therapies that may reverse the course of the disease process.

The Most Urgent Unmet Needs in the Treatment of Arthritis: (1) Potent anti-inflammatory drugs that spare gastric irritation. (2) New medications that will alter the course of the disease. (3) Home visits and nursing home visits by trained personnel for physical therapy, instruction, and care of the severely affected arthritic patient. Another unmet need is continued public education as to the benefits of simple aspirin therapy instituted and followed by a physician and also education as to the possible detrimental effects of untried "miracle cures" for arthritis.

MRS. HOWELL THOMPSON  
Cabot, Arkansas

November 12, 1975

Your newsletter arrived today, too late to comply with the October 31 mailing deadline. However, I do want to do all I can for the Arkansas Chapter of the Arthritis Foundation.

Through Dr. Ross, I was sent to the clinic and given therapy and other aids for rheumatoid arthritis. I followed the doctor's orders completely and the exercises suggested by the therapist, and after two and a half years I am much, much better. Being a 49-year-old "homemaker" with the children grown and married, I could follow directions better than others I know.

There have been quite a few cases of rheumatoid and "osteo" around the Cabot area. Some are 35- to 40-year-old working men. The Beebe, Arkansas, physicians have no understanding about arthritis at all. I hear this complaint from many, so our Government should provide better information to practicing physicians who apparently learned nothing concerning arthritis in medical school. Too, the public should be made more aware of the signs and see the doctor early to avoid severe crippling.

Research certainly needs government support in order to find the probable cause and best treatment. It is a very painful disease, but the person appears well in the early stages. Had I been a "working-for-a-living" victim, it certainly would have been a problem for me and my family. The pain is such you cannot function without "gritting" your teeth and holding your breath, and only a few seconds at a time.

So much of our Federal money is spent unwisely, I feel, such as the silly dancing of "vegetables" in downtown Little Rock for so-called

appreciation or understanding of the arts. That may be good, but it can be at the bottom of a list and arthritis research at the top. Like beautification of the freeways; that can be done after all roads are hard-surfaced for rural America.

We need to reevaluate our priorities. And arthritis, the cause and treatment, sure does need sincere consideration of our entire Congress. So many people are victims from all walks of life, and it certainly can cause pain.

I hope this letter is not too late.

MILTON T. FINCHER, JR.

It has been brought to my attention that Memphis, Tennessee, is being considered as a possible location for a children's arthritis care and research center which would deal with arthritis and related muscular and skeletal diseases.

My deep interest in this project stems from the fact that we have a 12-year-old daughter with lupus. She has been in and out of the hospital for months at a time over the past three years. After much delay and guesswork on the part of others and, on two separate occasions, nearly losing our daughter, Dr. Aram Hanissian, a specialist in this field and on staff at LeBonheur Children's Hospital, diagnosed and began treating the lupus. Now, nearly 18 months later, we have her in almost complete remission.

I feel very strongly that if we had had the added advantage of an arthritis research facility, perhaps she would not have had to endure as much as she did, suffering as she did.

A center such as this would serve as a means to educate the general public as to the importance of recognizing arthritis in a child. So many people think that these diseases are prevalent only in older people.

A center such as this could have supporting personnel for parents and for children, such as nursing care and a "big sister program," to give patients at home a chance to relate to someone other than parents.

It would need social workers to help parents find trustworthy care for the child to enable them to not be as confined.

Early detection of symptoms to enable doctors to begin treatment is very necessary. Physical therapy is also of prime importance for those afflicted with joint and limb diseases.

LeBonheur Children's Hospital and its doctors serve a seven-state area with an approximate population of three million people. I believe the size of the area involved alone would warrant a center such as is proposed for the Memphis area.



Little Rock, Arkansas

November 12, 1975

It is with great hope that we await any indications that there is a chance that Memphis might be chosen as the site for the new center. I feel that it would be such a rewarding addition to an already fine medical center.

ROBERT H. FISER, JR., M.D.  
Little Rock, Arkansas

November 3, 1975

I would like to address the Commission to needs that we have in arthritis in children of the State of Arkansas. Juvenile arthritis and rheumatic disease are estimated to be present in 3,000 children in Arkansas, and statistics suggest that over 800 of these children are crippled by arthritis. This letter will be addressed primarily from a pediatric point of view as I am Chairman of the Department of Pediatrics at the University of Arkansas for Medical Sciences.

We are attempting an overall, comprehensive care program for the child with rheumatoid arthritis, with overall orthopedic and pediatric health needs met within the State of Arkansas. One of the strongest points that is present in Arkansas is the active lay professional groups interested in this problem from all aspects. We have facilities to deal with long-term chronic diseases of children and a manageable population, with most of these patients cared for at the tertiary center of the University Hospital or Arkansas Children's Hospital complex and rapid feedback into the regional groups in the State for continuing care.

I think the urgent unmet needs are attempts to develop this comprehensive care network that are available not only within one to two specialized areas, but would also meet the day-by-day needs and rapid follow-up in the regional centers.

A unique approach that Arkansas has is its stable population group and ability for long-term follow-up studies. We also feel that unmet needs are the life history of juvenile rheumatoid arthritis beginning with close metabolic hormonal growth development studies early on as well as prospective longitudinal studies into adult life. The close association of pediatrics and medicine in this regard is imperative. The other area of value is the advantage of strong regionalization concepts, continued education for medical students and physicians, and the tying in of studies with the National Center for Toxicological Research through the testing of arthritic drugs in children.

It is obvious this is of major importance to the State of Arkansas. In summary, we would like to develop comprehensive care programs that would be available not only at a large center for ultimate upbringing of clinical care with the newest techniques and rapid flow of information, but also develop an outreach program where these individuals can be handled with an overall, comprehensive plan in the hometown communities.

I hope that these areas can be addressed by the Commission as we feel there is a tremendous need in this rural state for these studies.

LOTTIE RUTH KETSCHER  
Little Rock, Arkansas

November 12, 1975

I am not very good at letter writing, so will just offer suggestions:

Would be nice if Arthritis Foundation had its own arthritis clinic equipped with physicians in arthritis and hematology for adults and children.

Also trained therapist with pool therapy and other needed therapy. Have hot water pools to be available day or night.

Transportation to and from pool for those who are unable to drive.

A set-up similar to Levi Memorial Hospital in Hot Springs, at a more reasonable price.

More time and money spent on research, hoping to find a complete cure. Medicines that do not cause side effects. More time and study of why arthritis affects the blood, and medicines or something that rids the blood of the infection.

BETTY LOWE, M.D.

#### Testimony in Regard to Children with Arthritis

The most urgent unmet need for children with arthritis in Arkansas is lack of access and availability to comprehensive care for this chronic disease.

There is an urgent need for a central area of professional reference where these children could receive a complete evaluation from a medical, physical, and emotional standpoint. This needs to be a clinic setting in which pediatricians, physical therapists, social workers, and orthopedists are concentrating on this particular problem. These children then could be started on a comprehensive care program, most of which (physical therapy, etc.) should be available in their community.

This center should be developed around this core of people and should be structured in such a way that ongoing continuing education is offered to the physicians in the state, and research capability would be provided.

At the present time, children who have this disease are managed to the best ability of their physician (family practitioner or pediatrician), but these professionals have no referral source for backup, guidance, or advice in complicated cases.

Such a center can be developed at present through the University of Arkansas center for Medical Sciences Pediatric Department and Arkansas Children's Hospital. Professional people are available, but funds to establish a comprehensive clinic are lacking. Estimated incidence of JRA in Arkansas is 2,000 children. At present, we see a small core of approximately 30 to 50 children with this disease in our clinic, and have

two or three children in the hospital for varying problems associated with their disease. As continuing education occurs in this state, this group is rapidly expanding.

The above testimony is given from the viewpoint of a pediatrician who has been in active private practice in Arkansas for 10 years and is now trying to establish a more comprehensive care program for these children at ACH.

RON ROBINSON  
Little Rock, Arkansas

October 29, 1975

The purpose of this letter is to transmit to you written testimony for presentation to the National Arthritis Commission hearings in Little Rock, Arkansas, on November 12, 1975, at the downtown Holiday Inn. The following is my testimony.

For the past three years I have been actively involved as a volunteer in the work of the Arkansas Chapter of the Arthritis Foundation. My contribution has been primarily in the area of public information and education about this crippling disease and the important programs of the Foundation.

I would like to voice my firm opinion that the National Arthritis Act of 1974 should receive priority funding at the earliest date so that Federal programs can be strengthened in finding answers to this national health problem. For the millions of Americans suffering from this disease, the major thrust of Federal support should be aimed at the funding of medical research to find the cause and cure for arthritis in all its forms. Until that door has been unlocked through research, the disease will continue to be a crippling, living hell that restricts the productivity, happiness, and independence of those victims.

In addition, Federal funding should be granted for medical training so that patient care programs will be more readily available from skilled specialists in the area of rheumatology. To give a graphic example of this need, the current Little Rock telephone directory, for use by a metropolitan area of a quarter of a million people, only lists two rheumatologists under its "Physicians" section.

The rheumatologists in this region, both in private and health agency practice, are dedicated, hard-working medical professionals. However, they will need further assistance in the future as Little Rock continues to develop a major regional health care center.

One other area that requires Federal funding in the fight against arthritis is in the development of public and patient education programs about the disease. As public education chairman for the Arkansas Chapter of the Arthritis Foundation for the past three years, I have directed such an effort on a statewide basis and firmly believe that an expanded, continuing program of education is certainly in the public interest.



Why should such programs be funded? Why fund "PR-type" programs when the real need lies in the areas of research and patient care? These are frequently asked and legitimate questions that require explanation.

I think that public education programs on the disease and on help available to arthritis victims are important because:

- (1) The programs provide factual information on warning signs, treatment, and services at a time when arthritis quackery is at an all-time high. An estimated \$400 million is spent annually on false cures, fraudulent medicines and equipment, sometimes injurious medical treatment, and other bogus answers. Facts about the disease and services available are needed more than ever before.
- (2) The programs build a solid base of public awareness about arthritis so that interest in providing local and statewide help can be cultivated among service organizations, civic clubs, medical groups, and other public-minded segments of the community. The more people know about the widespread problem of arthritis, the more they will be motivated to lend their support to the effort. Public education programs will do that job.

My experience has been that the news media is very cooperative in telling the "arthritis story" when they are provided with well-prepared, accurate tools. Radio and television public service announcements, news releases, feature articles, photos, and other aids have received good reception by the Arkansas media.

In addition, the Arkansas chapter has provided localized brochures and other data to help arthritis victims learn about services available to them within the State. For example, a services directory prepared by the chapter earlier this year has received widespread dissemination. Over 18,000 copies of this booklet have been distributed in the last eight months, providing for the first time a comprehensive resource guide for Arkansas arthritics. This work should be continued and expanded through Federal funding.

There are many gaps to be filled in the information effort. The last film produced by the Federal Government on arthritis is now over five years old. No central information service for arthritis victims within the Government exists to give patients guidance on treatment and financial assistance. Plus, there are many, many more information areas which Federal funding can underwrite in meeting this health problem.

These types of programs should not be inflated to the point where they will take valuable funding away from the basic needs for research and medical training. However, on the other hand, to completely discount any consideration for providing information to the American public through federally funded communications programs would be unwise, since they provide important links in meeting individual needs. These communications programs should be incorporated into current health information services provided by the Government agencies and should be developed through new channels, particularly at the state level, in giving localized data.

I strongly encourage the National Arthritis Commission to recommend major appropriation to the provisions of the Act and commend to the Commission the desire for recommendation that arthritis information programs be considered for funding as a part of the total Federal effort.

Thank you very much for your consideration, and if you need further information, please let me know.

ERADAY TYSON  
Meridian, Mississippi

October 30, 1975

Through the successful efforts of my local doctor, I was admitted to the Mississippi Methodist Rehabilitation Center, Jackson, Mississippi, on August 11,

1975, and dismissed on September 26, 1975, suffering from acute muscle spasms, associated pain, and an inability to stand or walk as a result of chronic polymyositis.

I am deeply humbled and duly impressed by the efficient care and medical assistance that was given me by the entire staff of this new and modern facility. It is my pleasure now to express my sincere gratitude for the services rendered me by such dedicated people.

I am happy to report that during my stay at the center I witnessed remarkable improvements in many patients, and, in some cases, complete recovery from the crippling effects of arthritis and related musculoskeletal disorders.

I, more so than many, am aware of the urgent need for further state and/or Federal assistance to support hospitals such as the center in Jackson for I have found it impossible to obtain hospital insurance that will cover my chronic condition. Therefore, had it not been for their assistance in my critical need, I hesitate to ponder the condition I would be in this day.

I was not released from the center without being equipped with aids for my recuperative period at home. I was fitted for and given a wheelchair, walker, and other items to assist me in this endeavor. All of this, plus many tests, medications, therapy, comfortable accommodations, and meals, were provided for exclusively by appropriated funds by Federal and state agencies.

I have been unable to work since the latter part of July of this year due to this disability, but am pleased to state that due to the fact that I was privileged to take advantage of what the center has to offer persons suffering from this type of disease, I am now walking some each day, have even driven my car short distances, and have every confidence that this, too, will now improve.

It is my prayer that more money will be appropriated to provide the nation with the new programs deemed essential for the minimal effort

required to make greater progress in the eradication of this, the nation's number one crippling disease.

MICHAEL N. HARRIS, M.D.  
Little Rock, Arkansas

October 29, 1975

It is with great pride and appreciation that I am given the opportunity to write my testimony concerning the needs of the arthritic patients in the State of Arkansas and to inform you of the present programs being carried out in this State for the arthritics and how they need to be expanded.

Although it is trite to say, the most pressing need of all arthritics is to find the cause and then present a cure for these dread diseases. I am saying this because I feel that there needs to be a concerted effort to combine research projects and to secure better cooperation from all research centers in their programs. A joint collaboration of projects, I think, would bring a more rapid result than what is now being carried out in the form of a multidirectional effort with, in my opinion, no cooperation and without any concrete evidence of progress being made toward the ultimate goals.

Certainly, this area could be further expanded, but I feel that we can discuss this better in other meetings.

A more positive approach to drug research and availability of drugs to the public needs to be made. It does not serve any purpose for a physician to travel a thousand miles to a seminar and to be told by an expert that nothing does any good and nothing is better than aspirin. Although this may be true, I think we should present positive and negative views of all drugs. If there are drugs that look promising, they need to be made available to the public soon.

Certainly, I feel that the person presenting a seminar should present his views as to what medications he feels are showing promise and which ones he feels do not and will not prove to be beneficial. Also, he should, of course, state the drugs he thinks will not be made available to the public.

I am not saying that the drugs should not be tested, but at this time they are either getting bogged down in the bureaucratic confusion or they are being withheld for some type of political or selfish motive by drug companies and/or other organizations. There are drugs that the physicians have been told three to four years ago would be coming on the market soon that have not as yet come out. If they are not going to be on the market, the physician should be told. If they are being studied for other reasons, then I think the medical community should be appraised of these studies and the situation and status of these drugs. These areas, of course, I think could be funded, and this type of education of the practicing physician could be fairly easily done.

Even though an excellent attempt is being made, I think a more intense effort to purge the Mexico clinics should be made. If it is true that



certain drugs are being used, the physician needs to be told. If DMSO tablets are, indeed, really dexamethasone rather than DMSO, then the physician should be told of this. This is just one example.

A stronger effort needs to be made to refute some of the public notices of arthritic cures. As recently witnessed, the report from London was refuted; but certainly the press manages to put this in an extremely small area and in the corner of the want ads.

In Arkansas we have an outstanding Arthritis Foundation chapter which is serving the public, making great effort toward education of the public plus practicing physicians, and contributing to research in various ways.

We have a home-care program centered around a physical therapist and the practicing family physician. Arthritis clinics are set up in over twenty localities in the State for instruction of patients and review of the patients' general treatment, progress, and needs.

The Foundation also is participating with the Regional Medical Program in grants supporting further research, training of physical therapists, data banking, and public and professional education.

The Foundation cosponsors a Chair of Rheumatology at the University of Arkansas Medical Center and gives an educational scholarship to an outstanding physical therapy student.

Areas of improvement would be the addition of social services for instruction of patients both in economic problems and rehabilitative problems. A more intense effort to rehabilitate patients, with cooperation with the Arkansas Rehabilitation Service, would be admirable, and maybe some type of support financially in this area would help this come about.

The formation of group therapy sessions has been mentioned to me by several of my patients as an excellent addition to the overall program. This, of course, would serve as a focus of input by patients with each other and would maybe help in their obtaining insight into their general problems and would help them in better understanding their disease.

The effect of sessions such as this is very well shown by the Arkansas chapter's sponsoring of a physical therapy pool program twice a week at Saint Vincent Infirmary in Little Rock. Patients have formed a rather unique group and have banded together to exhibit extreme esprit de corps and have even had social gatherings. This has been very outstanding for my patients.

In a review of some of our needs which we think are needed here would be:

- (1) Expansion of the home-care programs to all areas of the State with addition of more personnel and possibly adding social services, even, possibly, a physician.
- (2) More support for the physical therapy pool program.

- (3) Some type of financial assistance to patients afflicted with these diseases so that they can pay for the expenses (medication, medical, and even transportation to and from medical facilities).
- (4) We, of course, need more physicians available who are qualified to treat arthritics and who are able and willing to administer antiarthritic drugs such as gold to the rheumatoid patient. This is a very great drawback in our state, and I am sure is a problem in other areas. Patients who would benefit possibly from gold, for instance, would have to drive long distances to receive their treatment. The cost of traveling is prohibitive, and the cost of the necessary follow-up of these patients is also quite great.
- (5) We need assistance in the area of pediatric rheumatology. There really is no one here with expertise in treating children with arthritic disease.
- (6) We also could use more rheumatologists so that a combined effort would be available to support the needs of arthritic patients. This would make more physicians available to the public for treatment and educational purposes.

Presently, there are only two physicians who are attempting to inform the remainder of the medical community concerning arthritic needs and who are helping present the Foundation's program to the physicians in the state. Dr. Louis Sanders and Dr. Eleanor Lipsmeyer are presently carrying out these functions.

The Arthritis Foundation, Arkansas Chapter, has a long-range planning committee, and its plans really are excellent and generally are along the same lines which I have mentioned. Hopes for future use of funds would also include the possibility of increasing the availability or number of beds available in an institution specifically trained and ready to treat patients with arthritic type illnesses.

Listing of priorities concerning the arthritic patients in the State of Arkansas and what the Medical and Scientific Committee of the Arthritis Foundation felt were the most pressing needs is available from the Arkansas chapter office. I have only touched the surface of the number of projects being carried out by our Arthritis Foundation.

Thank you once again for this opportunity of voicing my opinion.

ROSS HONEA  
Little Rock, Arkansas

October 29, 1975

My name is Ross Honea, and I am the Assistant General Agent for Pan American Life Insurance Company in Little Rock, Arkansas. I serve as a member of the Board of Directors of the Arkansas Chapter, Arthritis Foundation.

I would like to present testimony that I have researched concerning arthritis victims and their ability to gain financial benefits through

three types of insurance. The policies researched were life, hospitalization, and disability income.

Life Insurance: My survey reveals that if there is no presence of crippling or absence from work, and if there is no long history of steroid treatment, then there will probably be standard issue. A policy will probably be rated or declined based upon severe crippling, substantial work loss, or extended steroid treatment. No extra benefits are offered where the policy is rated, such as waiver of premium for disability, double indemnity, and guaranteed insurability. It is also suspected that extended steroid treatment can result in heart and/or kidney disease.

Hospitalization Insurance: In every instance where arthritis exists in the medical history of the applicant, an exclusion will be placed on a newly issued policy. The exclusion covers the full body and not just the area previously showing the disease.

Disability Income: Here we have several possible actions taken:

- (1) Exclusion, most likely.
- (2) Set a minimum elimination period (90 days), shorten the benefits (maximum 1 year), and rate increase.
- (3) Decline.

I find that a younger person with a medical history of arthritis is more likely to be rated or rated higher on life insurance and disability income if the policy is issued.

Concerning hospitalization insurance for the person who contracts arthritis subsequent to buying new insurance, again we have different claim procedures. Some companies do cover diagnostic testing, X-rays, and examination to actually diagnose arthritis. I would say the percentage would be about 50 percent that do cover these charges.

I feel, therefore, that the National Arthritis Act should put as much money as possible in research centers to find the cause and cure for a disease which causes the American public financial problems that cannot be overcome.

BASIL A. SMITH

November 12, 1975

After working with numerous arthritics around the State, it is my personal feeling that the most urgent need is in the area of arthritis research. This is the place to work to stop this disease.

The second area money should be spent in is care for the person who has arthritis. I feel this could be accomplished two ways: First, through education programs for the primary care physician so that he will be better equipped. Second, through the establishment of local physical therapy units equipped to provide a full range of needed therapy for



arthritis sufferers. All of this provided at a rate of pay based on income.

I hope these thoughts will be helpful to the Commission.

# REPORT OF THE NATIONAL COMMISSION ON ARTHRITIS AND RELATED MUSCULOSKELETAL DISEASES

## Volume I: The Art

(DHEW Pub. No. 76-1150)

## Volume II: Work G

(DHEW Pub. No. 76-1151)

## Volume III: Survey

(DHEW Pub. No. 76-1152)

**Volume IV, Part 1:**

(DHEW Pub. No. 76-1153)

**Volume IV, Part 2**

(DHEW Pub. No. 76-1154)

**Volume IV, Part 3**

(DHEW Pub. No. 76-1155)

**Volume IV, Part 4**

(DHEW Pub. No. 76-1156)

## Submitted Statements



Amazing Research.  
Amazing Help.

<http://nihlibrary.nih.gov>

10 Center Drive  
Bethesda, MD 20892-1150  
301-496-1080

NIH LIBRARY



4 0127 1039



DHEW Publication No. [NIH] 76-1155